USE OF FAMILY HISTORY TO IMPROVE COLORECTAL CANCER SCREENING OUTREACH AMONG ALASKA NATIVE PEOPLE

A

DISSERTATION

Presented to the Faculty

of the University of Alaska Fairbanks

in Partial Fulfillment of the Requirements

for the Degree of

DOCTOR OF PHILOSOPHY

By

Diana G. Redwood, M.S, M.P.H

Fairbanks, Alaska

December 2013

Abstract

Colorectal cancer (CRC) incidence and mortality among Alaska Native people are the highest of any ethnic or racial group in the United States. First-degree relatives (FDRs), which include parents, siblings, and children of CRC patients, are at increased risk. There is a paucity of data on predictors of screening adherence among Alaska Native FDRs, and the extent to which screening outreach is occurring within the Alaska Tribal Health System (ATHS) for FDRs. There is also a lack of data available on barriers and facilitators to increasing screening outreach efforts in this population. This study assessed the prevalence of CRC screening outreach to FDRs at Alaska tribal health organizations (THOs), use of family history information, barriers to CRC screening, and potential tools to improve CRC screening throughout the Alaska Tribal Health System (ATHS). The study also included a process evaluation of the Alaska Native CRC Family Outreach Program (2000-2012) based in Anchorage, Alaska. The process evaluation investigated the program's formation, evolution, and successes and challenges through a series of key informant interviews with program stakeholders. Lastly, an outcome evaluation was conducted of the Alaska Native CRC Family Outreach Program to assess predictors of screening adherence and results of screening among Alaska Native FDR program participants. The study found that CRC screening outreach was common in the ATHS, but significant barriers still exist. These barriers were especially notable for outreach to FDRs, including a lack of dedicated staff and resources. Key results of the process evaluation of the Alaska Native CRC Family Outreach Program included an incremental approach that led to a unique outreach program and revealed the need for dedicated staff to provide culturally competent patient navigation. Challenges identified included differing FDR outreach responses, health system data access and coordination, and relying on unstable grant funding for program sustainability. The outcome evaluation of the Alaska Native CRC Family Outreach Program found despite increasing programmatic outreach and FDR screening rates, a large proportion of Alaska Native FDRs were still due for screening. This was especially true among rural-dwelling and older FDRs. This study found that overall, CRC screening and awareness are increasing among the Alaska

Native population, including among FDRs. However, many Alaska Native FDRs remain unscreened. There is a critical need for more research into FDR barriers and facilitators to CRC screening, as well as how the ATHS can more systematically promote screening among this increased-risk population and reduce morbidity and mortality due to this preventable disease.

Table of Contents

Page

Page

Page

List of Figures

Page

Page

List of Tables

List of Abbreviations

ACA ..... Affordable Care Act
BRFSS ..... Behavioral Risk Factor Surveillance System
CDC ..... Centers for Disease Control and Prevention
CRC ..... colorectal cancer
CRCCP ..... Colorectal Cancer Control Program
CT ..... computerized tomography
DCBE ..... double-contrast barium enema
EARTH Study ..... Education and Research Towards Health Study
FAP ..... familial adenomatous polyposis
FOBT ..... fecal occult blood test
GPRA ..... Government Performance and Results Act
gFOBT ..... guaiac-based fecal occult blood test
HNPCC ..... hereditary nonpolyposis colorectal cancer
iFOBT ..... immunochemical fecal occult blood test
MMR ..... mismatch repair
MSI ..... microsatellite instability
NCHS ..... National Center for Health Statistics
THO ..... tribal health organization
RCT ..... randomized controlled trials
USPSTF ..... United States Preventive Services Task Force

List of Appendices

Page

Acknowledgements

I would like to acknowledge the contributions and support of the Director of the Alaska Native Epidemiology Center, Ellen Provost, DO, MPH, at the Alaska Native Tribal Health Consortium; as well David Espey, MD, at the Centers for Disease Control and Prevention Division of Cancer Prevention and Control; the Alaska Native Tribal Health Consortium Board of Directors; and the Indian Health Service. I would also like to acknowledge the support of the University of Alaska Fairbanks and my Doctoral Committee members: Ellen Lopez, PhD, MPH; Monica Skewes, PhD, Rhonda Johnson, DrPH, MPH, FNP, and Gabriel Garcia, PhD, MA, MPH. The findings and conclusions are my own and do not necessarily represent the official position of the Alaska Native Tribal Health Consortium, the Centers for Disease Control and Prevention, or the Indian Health Service.

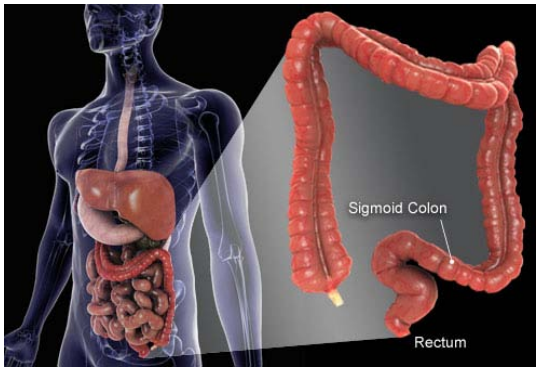
CHAPTER 1

General Introduction

Over the past four decades colorectal cancer (CRC) pathogenesis has been increasingly well elucidated. Epidemiological data outlining the demographic factors associated with colorectal cancer have also become available, included both protective and risk factors. Screening for colorectal cancer has come to be regarded as a primary method to both prevent colorectal cancer as well as find it early in the disease progression, resulting in reduced morbidity and mortality.

Anatomy

The human digestive system, also called the gastrointestinal system, processes food for energy in the upper portion (esophagus, stomach and small intestine). In the lower gastrointestinal system, water and mineral nutrients from digested food are absorbed and solid waste (stool) is formed that passes from the body through the colon and rectum (see Figure 1-1a). The colon, also called the large intestine or bowel, is about 5-6 feet long and is divided into four sections: the ascending colon, the transverse colon, the descending colon, and the sigmoid colon, which joins the rectum, which is the final 5-6 inches of the digestive system.



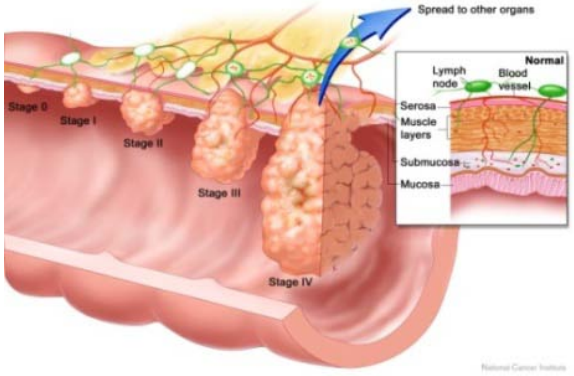


Figure 1-1a. Anatomy of human colon. Source: www.medicalinfo-3n.blogspot.com.
Figure 1-1b. Colorectal cancer disease progression. Source: National Cancer Institute.

Colorectal Cancer Pathogenesis

Colorectal cancer can start anywhere within the colon or rectum. Most colorectal cancers begin as polyps, small precancerous growths in the interior lining of the large intestine which progress very slowly into cancers (see Figure 1-1b).[1] Anatomic sub-sites for colorectal cancer are based on the International Classification of Diseases for Oncology codes for broad categories: proximal colon (codes C18.0 and C18.2-C18.5), distal colon (codes C18.6 and C18.7), rectum (codes C19.9 and C20.9), and other (codes C18.1, C18.8, C18.9, and C26.0).[2] The average time from progression of a polyp to cancer is 10 to 15 years.[3] Certain kinds of polyps, called adenomatous polyps or adenomas, are precancerous lesions formed from glandular structures in colon epithelial tissue and are the most likely to become cancer, though fewer than 10% of adenomas actually progress to cancer.[1] These types of polyps are common, and an estimated one-third to one-half of all individuals will eventually develop adenomas.[4] The vast majority (96%) of colorectal cancers are adenocarcinomas: “adeno-”, meaning “gland”, and “carcinoma”, meaning a malignant tumor evolving from epithelial tissue.[5] Colorectal cancers are classified by stages in the progression of the disease process. In Stage 1 the cancer has not spread to nearby tissue (*in situ* cancer). In Stage 2 the cancer has spread to other tissues, but not to the lymph nodes (local). In Stage 3 the cancer has spread to the lymph nodes (regional), and in Stage 4 it metastasizes to other organs in the body via the lymph system (distant).

Disease Progression

If found early when the disease is still at the local stage, the 5-year survival rate is 90%. If the disease has spread to the regional and distant stage at the time of diagnosis the 5-year survival rates are 70% and 12% respectively. Overall about 39% of colorectal cancer patients are diagnosed with localized-stage disease.[4] Colorectal cancers and some precancerous adenomas sometimes intermittently bleed resulting in small amounts of blood in the stool. Symptoms of colorectal cancer may include bleeding from the rectum,

blood in the stool or in the toilet after having a bowel movement, dark- or black-colored stools, a change in the shape of the stool, cramping pain in the lower stomach, a feeling

of discomfort or an urge to have a bowel movement when there is no need to have one, new onset of constipation or diarrhea that lasts for more than a few days, or unintentional weight loss.[4] However, colorectal polyps and early stage colorectal cancers usually do not cause symptoms, and in the absence of screening, they may go undetected until an individual presents at a symptomatic advanced stage.

Incidence and Mortality

United States Demographic Characteristics

Colorectal cancer mortality data in the United States (U.S.) is available from the National Center for Health Statistics (NCHS). Colorectal cancer incidence data comes primarily from the Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute. These data sources provide long-term trends on colorectal cancer in the United States. Cancer cases are classified according to the International Classification of Diseases for Oncology.[6] All incidence and death rates in these data sources are age-standardized to the 2000 U.S. standard population and expressed per 100,000 persons.[7]

In the United States alone, an estimated 102,480 (72%) cases of colon and 40,340 (28%) cases of rectal cancer were expected to occur in 2013, with an estimated 51,710 deaths, accounting for 9% of all new cases of cancer and 9% of all cancer deaths in the country.[7] Colorectal cancer is the third most common cancer in both men and women and the second most common cancer for males aged 40 to 79.[7] Rates of the disease vary widely by U.S. geographic area, with death rates tending to be lower in the Western states and higher in the South and Midwest. Incidence rates tend to be higher in the Midwest and Northwest regions of the country (see Figure 1-2).[4, 8]

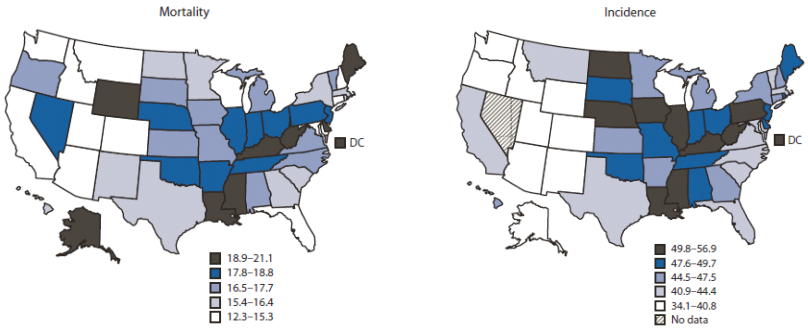


Figure 1-2. Age-adjusted colorectal cancer incidence and death rates per 100,000 population, U.S., 2007.[9]

Nationally, colorectal cancer incidence and mortality rates are highest among African American men and women, while rates are lower among the other major racial/ethnic groups (Asian American/Pacific Islander, Hispanic/Latino, and American Indian/Alaska Native) than rates among Non-Hispanic Whites.[4] Among American Indian and Alaska Native people overall incidence and death rates of colorectal cancer are similar to the United States White population.[7] However, American Indian and Alaska Native people are a heterogeneous population, and rates of colorectal cancer among American Indian and Alaska Native groups vary considerably throughout the United States.

Alaska Native Demographic Characteristics

Cancer is the leading cause of death among Alaska Native (AN) people. Data collected as part of the Alaska Native Tumor Registry demonstrate that colorectal cancer is the second leading cause of cancer mortality behind lung among Alaska Native people and the leading incident cancer.[10-12] For the period, 2004-2008, the Alaska Native age-adjusted colorectal cancer mortality and incidence was about twice that of U.S. Whites (see Figure 1-3);[13] a trend which also held for the period, 2005 to 2009, in which the colorectal cancer incidence rate in Alaska Native men and women was two times the rate in U.S. Whites (84 vs. 43/100,000).[9, 14] Alaska Native colorectal cancer incidence and mortality rates are also about twice those of all Alaskans.[4, 7]

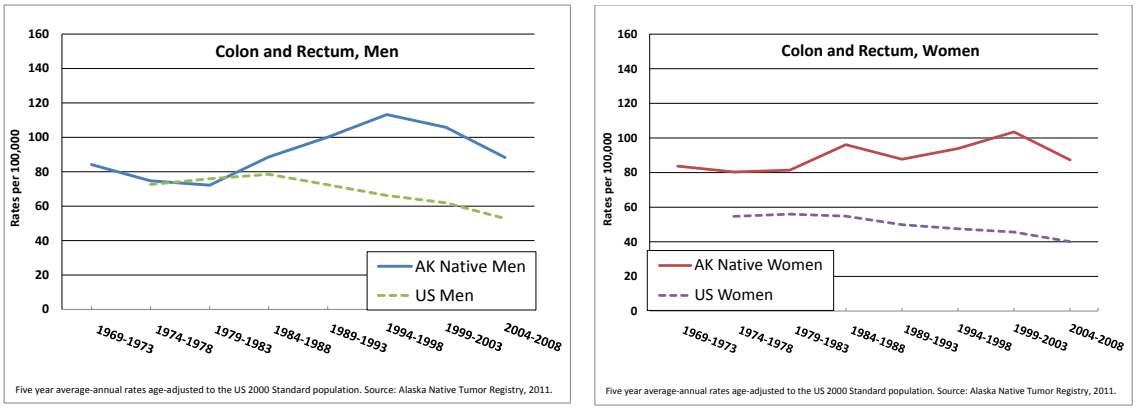


Figure 1-3: Five-year average annual age-adjusted cancer incidence rates, Alaska Native people, 1969-2008 and U.S. Whites, 1974-2008.

In sum, the colorectal cancer incidence and mortality rate among Alaska Native people is the highest of any ethnic or racial group in the U.S.[15] Furthermore, Alaska Native people experience the highest colorectal cancer incidence rate of all Native American groups with the rate varying five-fold between Alaska Native people (102.6 per 100,000) and American Indians from the Southwest U.S (21.0 per 100,000) (see Figure 1-4).[15-17]

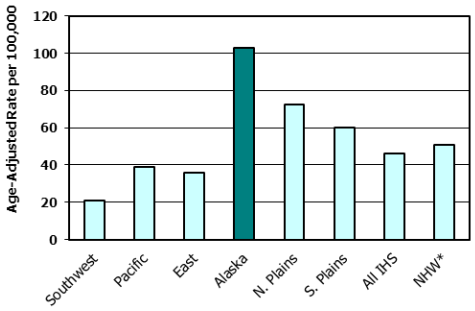


Figure 1-4: CRC incidence rates by select Indian Health Service Region Contract Health Service Delivery Area (CHSDA) counties, 1999-2004. NHW=non-Hispanic Whites.[16]

Colorectal cancer screening efforts at Alaska tribal health organizations statewide have documented identification of adenomatous polyps in 30% to 50% of patients. This stands in contrast to a national study of Medicare beneficiaries that reported an average polyp rate of 24%.[18] For the most recent period (2005 to 2009) for which data are available there were 301 cases of invasive and 36 cases of *in situ* colorectal cancer diagnosed

among Alaska Native people (154 men and 147 women).[14] Unlike national trends, the rates of colorectal cancer were similar for Alaska Native men and women, and colorectal cancers occurred proportionally in the same regions of the colon (41% in the proximal colon, 29% in the distal colon, and 28% in the rectum) as the U.S. White population.

Age-specific rates of colorectal cancer are higher among Alaska Native people as compared with U.S. Whites for all age groups, especially for Alaska Native people aged 70 to 79 (see Figure 1-5). Age-specific incidence rates for Alaska Native people are double those of U.S. Whites for ages 30 to 39 (11.3 vs. 5.6/100,000) and 40 to 49 (45.1 vs. 19.8/100,000).[14] The Alaska Native colorectal cancer *in situ* rate was four times higher than among U.S. Whites. As for invasive cancers, the incident rate was two times lower for localized colorectal cancer among Alaska Native people as compared with U.S. Whites, but twice as high for regional and distant cancers, which are the more advanced and difficult to treat cancers. An analysis of diagnosis by colorectal cancer stage found that 59% of Alaska Native colorectal cancers were diagnosed beyond the local stage. However, at each stage of diagnosis, the five-year relative survival rate was similar between Alaska Native and U.S. White populations.

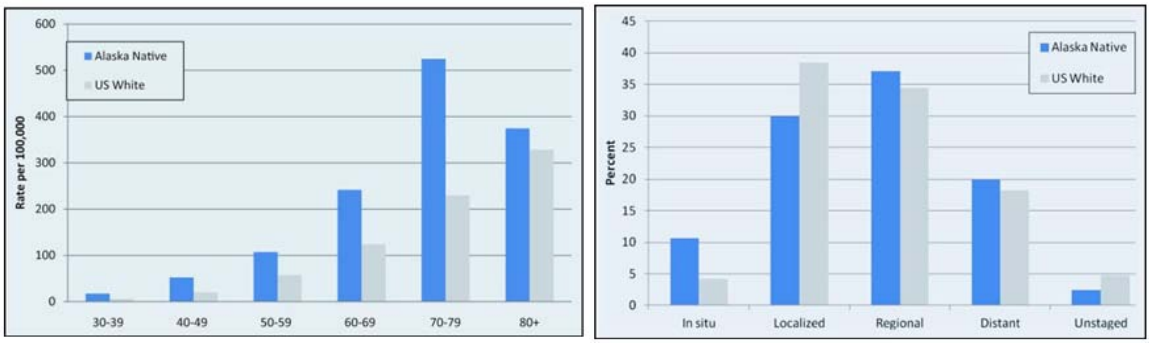


Figure 1-5: Age-specific CRC incidence rates and stage at diagnosis, Alaska Native People and U.S. Whites, 2005-2009.[14]

Incidence and Mortality Trends

In the United States overall, colorectal cancer mortality rates have declined 30% over the past two decades; from 2000-2009, colorectal cancer declined 3.0% annually.[7] Long-term incidence rates have also been declining in men and women, with an increase in the

incidence of the disease for men during 1975-1985, declines during 1985-1995 for men and women, a short non-significant increase from 1995-1998, and then marked declines from 1998-2006 for both sexes.[7]

In the 1950s, cancer ranked low among causes of death among Alaska Native people. Over the last 50 years cancer has increased to now ranking as the leading cause of death among Alaska Native people. In contrast to the declining United States death rate from colorectal cancer, the Alaska Native colorectal cancer death rate has not been declining.[19] The incidence of colorectal cancer has significantly increased in the Alaska Native population since 1969.[15, 16] Data from the most recent period available from the Alaska Native Tumor Registry (2005 to 2009) show that the Alaska Native incident rate appears to be declining from the 1990s. However, this decreasing trend was not statistically significant, and colorectal cancer continues to account for the greatest cancer burden among Alaska Native people.[14]

Colorectal Cancer Screening

Declining trends in colorectal cancer incidence and mortality among adults 50 years and older have been largely attributed to increases in colorectal cancer screening.[2, 4, 9, 20, 21] Screening has the potential to prevent colorectal cancer by detection and removal of precancerous polyps in the colon and rectum, as well as detecting cancer at earlier, more treatable stages.[3, 22, 23] The evidence for screening effectiveness is primarily based on large prospective randomized controlled trials with guaiac-based fecal occult blood tests (gFOBT) ,which demonstrated significant reductions in colorectal cancer mortality of 15% to 33%, and large randomized controlled trials with flexible sigmoidoscopy which found that flexible sigmoidoscopy reduced colorectal cancer incidence by 32% and mortality by 28%.[24, 25]

The primary goal of colorectal cancer screening is cancer prevention, and the long lead-time from precancerous polyp to colorectal cancer presents a window of opportunity for

screening and intervention.[26] It has been estimated that if all precancerous polyps were identified and removed before becoming cancerous, colorectal cancer incidence and mortality could be reduced by 76% to 90% and 70% to 90%, respectively.[3, 27] This also has profound implications for healthcare systems in the form of unrealized financial savings.[28] The United States spends roughly $14 billion each year on colorectal cancer treatment.[29-31] In 2006 alone, an estimated $288,468 in productivity was lost per colorectal cancer death.[9] As the United States population ages, the economic burden of this disease among individuals aged 65 and older is estimated to increase by 50-89% through 2020.[29] If United States cost estimates are projected for Alaska Native people, the treatment costs alone for 100 persons with colorectal cancer would be more than $10 million annually.[29, 30]

The United States Healthy People 2020 target for colorectal cancer screening is 70.5%,[32] and the Centers for Disease Control and Prevention (CDC) National Colorectal Cancer Control Program (CRCCP) has set a goal to increase colorectal cancer screening rates from about 64% to 80% among adults aged 50 years and older by 2014.

Screening Methods

Accepted colorectal cancer screening options include tests that primarily detect cancer (stool tests) and those are more likely to detect cancer and precancerous growths, including flexible sigmoidoscopy, colonoscopy, computed tomography colonography (also known as virtual colonoscopy), and double-contrast barium enema. Although all these screening tests are nationally recommended, there are significant advantages and disadvantages to each test in terms of patient discomfort, time requirements, invasiveness of test, and recommended intervals and required follow-up. These tests may be used alone or in combination to improve the sensitivity of the test or if the initial test cannot be completed.

Fecal Occult Blood Tests

Fecal occult blood tests (FOBTs) detect blood in the stool resulting from colorectal cancer and some precancerous adenomas.[33] Studies have reported specificities of guaiac-based fecal occult blood test for detecting advanced neoplasia from 63% to 97% and of immunochemical fecal occult blood tests from 62% to 99%.[34-49] Patients collect stool samples for the fecal occult blood test using a specimen collection stick and spreading it on the fecal occult blood test card. Patients then return the fecal occult blood test cards to their provider or to a laboratory for evaluation. Positive fecal occult blood tests require colonoscopic follow-up to rule out presence of polyps or cancer. Guaiac-based fecal occult blood test (gFOBT) detects the heme portion of hemoglobin. However, bleeding from upper intestinal tract lesions, including erosions or ulcers from *Helicobacter pylori* (*H. pylori*) infection or non-steroidal anti-inflammatory medications, as well as the presence of non-human heme from ingesting red meat or ingesting foods with peroxidase activity (e.g. spinach), can cause false positive results. Ingestion of vitamin C may cause false negative tests. Dietary and medication restrictions are therefore necessary for maximizing the accuracy of guaiac-based fecal occult blood tests.

The immunochemical FOBT (iFOBT) detects the globin portion of human hemoglobin. As globin is degraded as it transits the upper intestinal tract, the immunochemical fecal occult blood test is more specific for lower intestinal bleeding. Therefore, dietary and medication restrictions are not required with the immunochemical fecal occult blood test. For these reasons the immunochemical fecal occult blood test has been shown to have better specificity and equal or better sensitivity than guaiac-based fecal occult blood tests for the detection of colorectal neoplasms.[48-52] However, because hemoglobin degrades during colon transit, commonly used fecal blood tests, such as guaiac-based fecal occult blood test or immunochemical fecal occult blood test, are proportionately less sensitive for colorectal cancer on the right side of the colon.[53, 54] There has been a growth in the number of commercially available versions of the guaiac-based fecal occult blood test

and immunochemical fecal occult blood test on the market, which vary in their sensitivity and specificity for colorectal cancer.

Endoscopy (Flexible Sigmoidoscopy and Colonoscopy)

Compared with stool tests, endoscopy (flexible sigmoidoscopy or colonoscopy) requires specially trained providers, is resource intensive, and requires patients to undergo invasive bowel preparation and screening procedures. However, endoscopy can prevent cancer by detecting and even removing precancerous polyps from the colon and rectum.[33, 55, 56] For flexible sigmoidoscopy, a short thin flexible lighted tube with a camera (sigmoidoscope) is inserted into the rectum to check for polyps or cancer inside the rectum and the sigmoid colon (the lower third of the colon). The procedure is usually performed without sedation and requires minimal bowel cleansing (laxatives). Although sigmoidoscopy does not examine the entire colon, approximately 60-80% of patients with significant findings in the colon will be identified with this test.[24, 55] Flexible sigmoidoscopy requires much less time and preparation than a colonoscopy, but if a tumor or polyp is found during the exam then a follow-up colonoscopy is necessary.

In a colonoscopy, a longer thin flexible lighted tube with a camera lens is inserted into the rectum. This scope can be advanced through the entire colon all the way to the ileocecal valve, located at the juncture between the colon and the small intestine (ileum). The colonoscope can check for polyps or cancer similarly to flexible sigmoidoscopy, but is the only method that can also remove polyps during the procedure. However, both sedation and a full bowel preparation are necessary for colonoscopy, and it has the highest risk of complications, including bowel tears or bleeding. Because of the sedation used during the exam, patients are generally not allowed to go home without an escort, such as a friend or family member who can watch over them after the screening exam. Tumor and polyp removal methods include clipping, burning with a laser, and/or lassoing the polyp and cutting it off from the wall of the colon. Tissue biopsies are sent to a pathology laboratory for histological sub-typing. Depending on the severity of the polyp,

different surveillance follow-up intervals may be recommended. In recent years endoscopy quality assurance standards, including adenoma detection rate, complications rate, bowel preparation quality, cecal intubation rate (for colonoscopy), and colonoscope withdrawal time have started to be used by providers to provide benchmarking for quality improvement and more consistency of screening endoscopic procedures.[57-59]

Other Screening Tests

Double-contrast barium enema (DCBE), a radiological examination of the colon, does not require sedation but requires a full bowel preparation, and a follow-up colonoscopy is necessary if abnormalities are detected. Computed tomographic (CT) colonography uses low dose radiation to obtain an interior view of the colon using special x-ray equipment linked to a computer. The bowel-cleansing regimen for CT colonography is similar to that of a colonoscopy, and if abnormalities are detected then a follow-up colonoscopy is necessary.

Biologically, only a small proportion of precancers bleed but they all exfoliate cells into stool. A new screening test in development detects the colorectal cancer genetic molecular markers exfoliated in stool (stool DNA, or sDNA test). Due to the genetic heterogeneity of colorectal neoplasia, multiple DNA markers need to be assayed. However, early clinical studies suggest high sensitivity (85%-96%) and specificity (87%-91%) for both colorectal cancer and pre-cancerous polyps, and the sDNA test has been endorsed by the American Cancer Society.[24, 60] This test requires a single stool collection, no dietary or medication restrictions, can be sent through the mail, and subjected to freezing with no loss of test performance.[61-63]

Screening Methods for Alaska Native People

Colorectal cancer screening using conventional guaiac-based fecal occult blood test has been discouraged among Alaska Native populations due to a high prevalence of *H. pylori* infection, which affects up to 75% of Alaska Native populations living in rural areas.[64-66]

H. pylori can cause erosions, ulcers, hemorrhagic gastritis, and less commonly mucosa-associated lymphoid tissue lymphoma (MALT) and adenocarcinoma of the stomach[40, 64, 67, 68] all of which can cause upper gastrointestinal bleeding and false positive tests with gFOBT. Accurate use of the guaiac-based fecal occult blood test is further complicated by the Alaska Native diet, which tends to be high in red meat, causing further excessive false positive guaiac-based fecal occult blood tests and poor specificity of the test.[69, 70] Haverkamp et al. (2011) found that Alaska had the lowest percent (54%) of tribal providers nationally that reported using fecal occult blood tests for colorectal cancer screening.[71] The high prevalence of *H. pylori* infection and its association with false positive guaiac-based fecal occult blood test results have led to a reliance on endoscopy, particularly colonoscopy, as the preferred colorectal cancer screening method in this population.[67, 72] Although flexible sigmoidoscopy is available at several tribal health facilities statewide, colonoscopy is the primary screening method used throughout Alaska.[73] Some reasons for this are the high false positive fecal occult blood test rate, the high incidence and mortality of colorectal cancer among Alaska Native people, a high number of colorectal cancers on the right side of the colon, which cannot be detected by flexible sigmoidoscopy, and a national trend towards using colonoscopy for screening.[14, 72, 74]

Recommended Screening Intervals

Recommended colorectal cancer screening intervals vary by test, and have changed over time due to advances in clinical practice and research. Being screened at the recommended frequency increases the likelihood that colorectal cancer can be detected at an earlier, more curative stage, with less extensive treatment and recovery time for the patient.[4] The first formal guidelines for colorectal cancer screening in average-risk adults were issued by the American Cancer Society (ACS). In 1997 under the sponsorship of a consortium of gastroenterology societies, a panel was convened by the United States Agency for Health Care Policy and Research to create a set of clinical practice guidelines for colorectal cancer screening for persons aged ≥50 which also included

recommendations for high-risk individuals.[75] Those guidelines were then updated in 2003 to reflect advances in the research literature, including not rehydrating fecal occult blood tests, decreasing the screening interval for double contrast barium enema, recommending colonoscopy for diagnostic follow up and for screening patients with a family history of hereditary nonpolyposis colorectal cancer, and providing guidance on appropriate time intervals for surveillance after positive findings.[76] Guidelines for surveillance after screening have been updated, most recently in 2012.[77]

In 2008 the United States Preventive Services Task Force (USPSTF) convened to review the previous guidelines and recent scientific literature as a collaboration between the American Cancer Society, the American College of Radiology and the U.S. Multi-Society Task Force on Colorectal Cancer (a consortium representing the American College of Gastroenterology, the American Society of Gastrointestinal Endoscopy, the American Gastroenterological Association, and representation from the American College of Physicians). The USPSTF published a set of guidelines that recommends routine colorectal cancer screening for average-risk men and women, ages 50-75, using annual high-sensitivity guaiac-based fecal occult blood tests or immunochemical fecal occult blood tests; flexible sigmoidoscopy every five years combined with high-sensitivity fecal occult blood testing every three years; or colonoscopy every ten years. Recommendations for double contrast barium enema x-ray and CT colonography are every five years. Based on the accumulation of evidence sDNA testing has now been included as an acceptable screening option, although the appropriate interval for follow-up has not yet been established.[23, 24] For healthy adults aged 76 to 85 without significant comorbidities the USPSTF recommends screening on a case-by-case basis.

Screening Algorithms

There are many colorectal cancer screening algorithms used as decision support tools for providers. International screening decision support tools vary slightly, but all follow the same pattern, with risk level determined by the number and type of relatives diagnosed

(i.e. first- or second-degree), the age at diagnosis and the presence of other high-risk features, i.e. mutation status for cancer predisposing genes if present in the family. These algorithms provide guidelines for screening and follow-up care, appropriate risk management and stratification of patients, and help protect providers against medical liability, such as the CRICO/RMF CRC Screening Algorithm used by Harvard University (www.rmf.harvard.edu/~/media/Files/_Global/KC/PDFs/RMFCRC.pdf). An Alaskan example is given below (see Figure 1-6) of the Anchorage Neighborhood Health Center (ANHC) screening program algorithm which provides no-cost fecal occult blood tests and follow-up colonoscopies for low income uninsured patients in Anchorage, Alaska.[78]

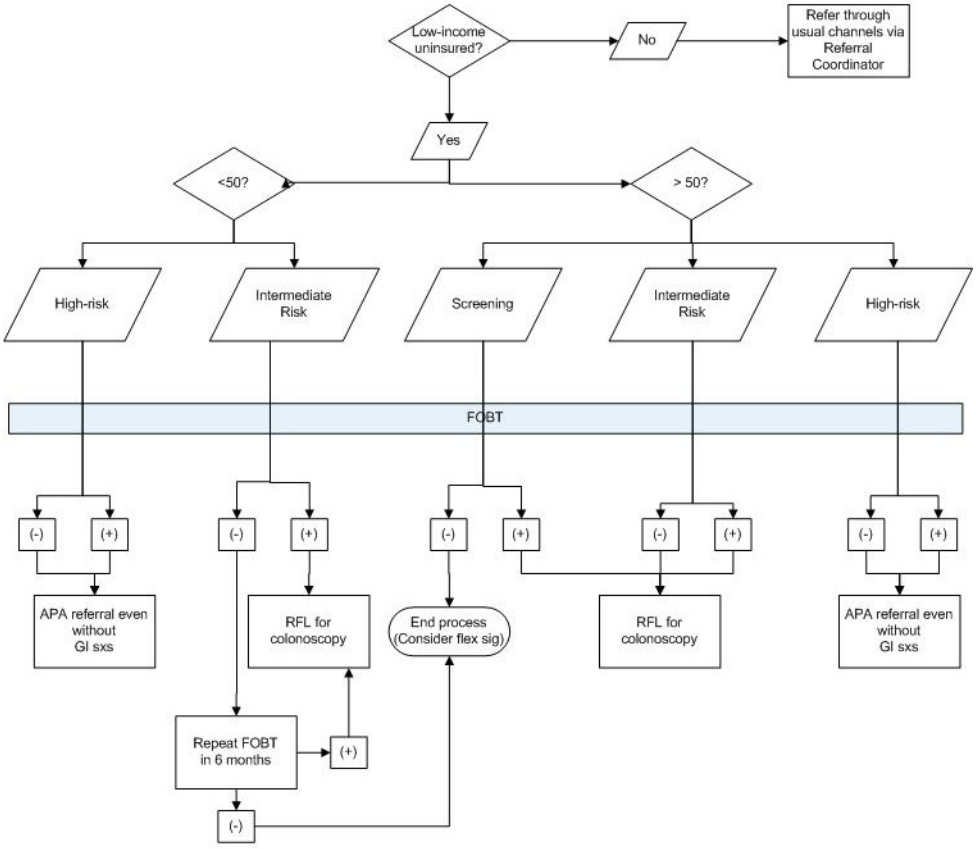


Figure 1-6. Referral flow chart, Anchorage Neighborhood Health Center, 2009.[78]

Screening Adherence

Predictors of Screening Adherence

There is a wide array of colorectal cancer screening methods available, and research on patient preference and adherence has found many different patterns of use by geography, race/ethnicity, sex, and age group. Lower income and education, and being from a racial minority group have been found to be barriers to colorectal cancer screening, even among insured populations or populations for whom cost barriers are removed.[4, 79-81] Cultural differences also play a role. One study of ethnically diverse focus group participants found that Hispanic men in the study were reluctant to get screening due to embarrassment and fear of exposure. African American men reported a general mistrust of physicians and the medical system, and Chinese men preferred to use Eastern forms of medicine over Western medical care.[82] A study of American Indian people living in the U.S. Midwest found that tribal cultural barriers related to colorectal cancer screening relate to lack of American Indian or Alaska Native healthcare providers or patient navigators, non-culturally-specific education, and lack of preventive care.[83] In some areas elders may primarily speak their own native language instead of English, such as on the Navajo reservation and in western Alaska, which may also decrease uptake of colorectal cancer screening.[83]

Because there are several nationally recommended colorectal cancer screening tests, each of which varies by frequency, accuracy, preparation required, and discomfort and cost, patients may have trouble determining which screening test to select. Jones et al. (2010) found that patients who were confused about screening tests were significantly more likely to be non-adherent to screening than those who were not confused, and those who discussed two or more options with their clinician were more likely to be confused about which test to undertake.[84] Many barriers and facilitators are also screening test-specific such as fear of pain associated with colonoscopy, or discomfort with collecting stool samples.[85] Additional barriers to screening are lack of health insurance, out-of-pocket

costs, and lack of awareness of the importance/benefits of colorectal cancer screening.[4, 86-88] Overall, provider recommendation, especially primary care providers, has been found across studies to be a major facilitator of screening adherence.[79, 89-92]

Many other factors also place a role in screening adherence, which screening tests patients elect, and at what age they choose to get screened, including fear/embarrassment, personal/social circumstances, specific screening method-related concerns, difficulty understanding test instructions, preference for screening tests other than the one offered by a provider, language issues, and being up-to-date with other cancer screening exams.[87-89, 93-99] One survey reported that 31% of respondents in the United States would choose not to be screened for colorectal cancer even when their preferred screening test was offered.[100] Furthermore, data from the National Health Interview Survey (NHIS), the National Cancer Institute Health Information National Trends Survey (HINTS), and other studies point to associations between colorectal cancer knowledge, awareness, and intention to screen with screening receipt.[101-104] Results from the 2005 National Health Interview Survey showed that the most commonly reported reason for not have a colorectal cancer screening was "never thought about it."[105]

Theoretical Constructs Related to Screening Adherence

Several theoretical constructs may influence colorectal cancer screening behavior including salience and coherence, perceived susceptibility, self-efficacy, and social influence.[106, 107] Cultural background, cancer beliefs, screening perceptions and cues to action all inform an individual's sense of their perceived risk and benefit of screening (see Figure 1-7 below).

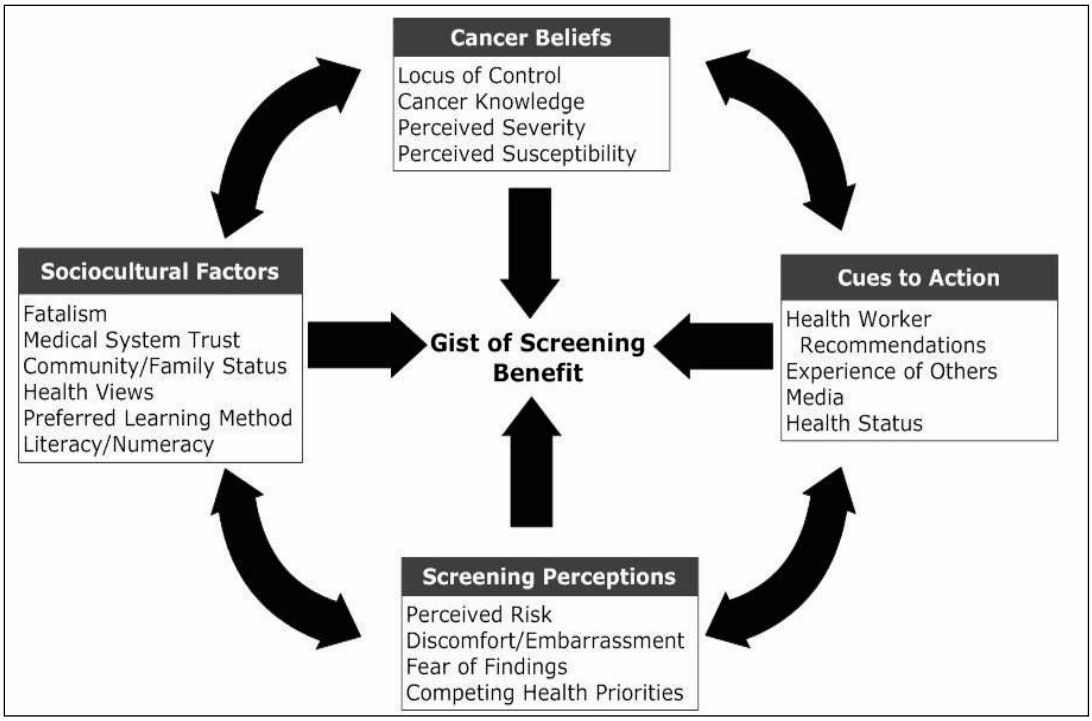


Figure 1-7. Theoretical model of CRC screening in underserved populations. Adapted from Indian Health Services Clinical Rounds presentation by David Perdue, MD, MSPH, American Indian Cancer Foundation, March, 2013.

Theoretically based studies have the advantage of using systematic approaches to examine screening adherence. The Stages of Change theory (pre-contemplation, contemplation, preparation, action, and maintenance) evidenced in the Transtheoretical Model (TTM: behavior changes occur in stages on a continuum rather than as a single discrete event) has been used to model colorectal cancer screening behaviors in different sub-populations,[93, 108] as has the Health Belief Model (HBM: perceived benefits, perceived barriers, perceived risk and perceived severity).[109-114] For example, one study used the Health Belief Model, along with elements of the TTM to investigate if individuals were more likely to obtain colorectal cancer screening if they perceived themselves to be susceptible to colorectal cancer, perceived the consequences of colorectal cancer to be severe, perceived many benefits of colorectal cancer screening, and perceived barriers to screening as relatively low.[111] The authors found that among siblings of patients with colorectal cancer, adherence and stage of adoption were

significantly related to perceived benefits, barriers and susceptibility. Barriers to screening decreased as stage progressed from pre-contemplation to maintenance. Constructs from the TTM were more associated with screening than the HBM and dual process models among this group of mostly Caucasian, middle class, well-educated siblings of colorectal cancer patients.[111]

Another study used the TTM to identify perceived benefits and barriers of fecal occult blood tests, sigmoidoscopy and colonoscopy among first-degree relatives (FDRs) of colorectal cancer patients to determine if they differed by stage of screening adoption (pre-contemplation, contemplation, and action).[93] The authors used the TTM to identify pros and cons (similarly to the Health Belief Model's benefits and barriers) to understand how changes in perceived benefits, barriers, and movement across stages led to behavior change around colorectal cancer screening (fecal occult blood test, sigmoidoscopy, and colonoscopy) among a group of mostly Caucasian middle class FDRs living in the U.S. Midwest. Benefits identified by this group of FDRs included finding cancer early, decreasing colorectal cancer mortality risks, freedom from worry about colorectal cancer and reassurance of being cancer-free. Most of the FDRs agreed with benefits of screening. Despite this fact, the majority was still in the pre-contemplation stage (had never thought about getting screened themselves). The study found that more than 64% of FDRs were in pre-contemplation, 15% were contemplating and 21% were in action for colonoscopy. Age was not related to colonoscopy stage of adoption. Participants in the action stage were more than twice as likely as pre-contemplators to believe in the benefits of colonoscopy to help find colorectal cancer early. Pre-contemplators cited barriers including healthcare provider not recommending screening (94%), colonoscopy being too embarrassing or painful (49%), and that they did not need it because they had no symptoms (45%). Interestingly, contemplators were twice as likely as pre-contemplators to report that they were afraid to have a colonoscopy because they might find out that something was wrong.[93] However, the study had a cross-sectional design and so was

unable to examine within-individual changes in benefits and barriers across stages over time, which would require a more longitudinal framework.

Although theoretical constructs have been used to help inform research on screening adherence, much is still not understood about the social processes and settings that influence colorectal cancer screening behavior, especially for sociodemographic subpopulations, such as Alaska Native people.

Alaska Native Predictors of Screening Adherence

In addition to the predictors of screening adherence mentioned above, additional barriers experienced by Alaska Native people, including geographic barriers and cost of travel may play a role in underutilization of colorectal cancer screening.[72] Southcentral Foundation (SCF), a tribal health organization based in Anchorage, Alaska, conducted telephone interviews in 2010 with a small group of Alaska Native men and women ages 50-75 about barriers and facilitators to colorectal screening by either flexible sigmoidoscopy or colonoscopy. These results were shared with tribal leadership but are not yet published or available for external review. However, similar barriers as national studies were reported in the study conclusions. Of note was that there was no difference in the barriers reported by both screened and unscreened individuals; therefore, further as-yet unrecognized factors may play a role in why Alaska Native individuals choose to obtain or not obtain colorectal cancer screening.

Screening Prevalence

United States Colorectal Cancer Screening Trends

Although colorectal cancer incidence and mortality can be reduced substantially through screening and early detection, the United States colorectal cancer screening rate remains far lower than other screen-detectable cancers including breast and cervical cancer.[115] Nationally, as of 2010, a total of 65.4% of Americans aged 50 to 75 years reported being up-to-date with colorectal cancer screening, where “up-to-date” means the respondent

had a fecal occult blood test (FOBT) during the previous year, a sigmoidoscopy within the previous five years and a FOBT within the previous three years, or a colonoscopy within the previous ten years.[9] This represents an increase in the screening rate from 2002, when only 51.9% of Americans were screened as recommended, which was even lower (40.9%) in 1997.[9] However, 22 million people in the United States are still not up-to-date with recommended colorectal cancer screening.[9, 105] United States Behavioral Risk Factor Surveillance System data (2008) show that screening rates are highest in the Northeast region of the country, with Massachusetts reporting the highest screening rate in the nation (75.8%), compared with the lowest rate reported in West Virginia (54.7%).[9] The percent of people up-to-date with screening either by FOBT or endoscopy is fairly similar among men (54.9%) and women (52.0%).[4] Screening prevalence is lower among people aged 50 to 64 (49.1%) compared to those 65 years and older (58.1%), and is especially low among those who are non-White, who have fewer years of education, who lack health insurance coverage, or are recent immigrants. Overall screening rates are highest among White non-Hispanics (56.0%), followed by African Americans (48.9%), Asians (47.9%), Hispanic/Latinos (37.2%), and American Indian/Alaska Natives (33.1%). Screening rates have been increasing nationwide for American Indian/Alaska Natives, with Indian Health Service (IHS) data showing a national average of 37% in 2012 compared with 33% in 2009. Screening rates vary considerably by Indian Health Service region from 24% in the Phoenix Area to 55% in Alaska.[116] There is an overall increasing trend of screening among those with a higher education, with 64.5% of Americans with 16 or more years of education reporting have been screened versus 37.3% of those with 11 or fewer years of education. The contrasts in screening rates are especially notable by insurance status: just 19.5% of those without insurance reported screening, compared with 55.7% of those with health insurance. Likewise, those who were born in the United States (55.0%) or who had been in the United States for ten years or more (41.9%) were more likely to be screened than those who had been in the United States less than ten years (28.0%).[4]

Over the past decade, patterns of use of colorectal cancer screening methods have shifted (see Figure 1-8), with declines in the use of flexible sigmoidoscopy and stool blood tests, increases in the use of colonoscopy, and a phasing out of double contrast barium enema (DCBE) as a first-step screening test.[117, 118] Endoscopy (primarily colonoscopy) is currently the predominant screening modality in the United States; 62% of United States Behavioral Risk Factor Surveillance System (2008) respondents aged 50 to 75 years reported lower endoscopy within the past ten years.[9] However, although colonoscopy usage has been increasing rapidly among nearly all population subgroups, there are differences in usage rates. An analysis by Klabunde et al. (2011) of data from the 2000, 2003, 2005, and 2008 National Health Interview Survey found that Hispanics reported less colonoscopy use than non-Hispanic Whites did.[118] Similar patterns were observed for people with less than an high school education (versus those with more than an high school education); recent immigrants (versus individuals born in the United States); people with family income <200% of Federal Poverty Level (versus those with family income >500% of Federal Poverty Level); the uninsured (versus people with health insurance coverage); those with no usual source of care (versus individuals who reported having a usual source of care); and people who had no physician visits in the past year (versus those with two or more visits).[118]

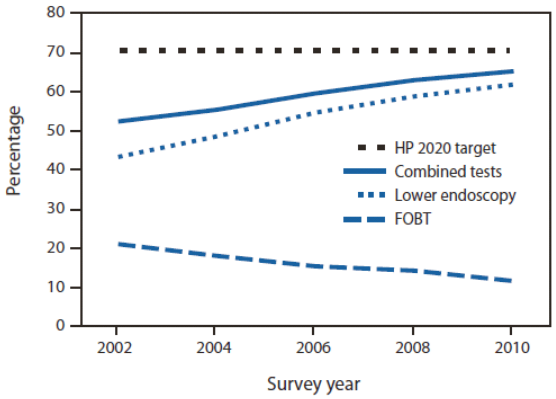


Figure 1-8. CRC screening data from BRFSS. Percentage of respondents aged 50--75 years who reported receiving a fecal occult blood test (FOBT) within 1 year and/or a lower endoscopy within 10 years and Healthy People 2020 (HP 2020) target --- Behavioral Risk Factor Surveillance System (BRFSS), United States, 2002, 2004, 2006, 2008, and 2010.[9]

These overall trends in endoscopy use have led to studies which have noted that demand for endoscopic colorectal cancer screening could outstrip supply at current rates of increase.[119, 120] In 2000, the Centers for Disease Control and Prevention (CDC) conducted a nationwide study to determine if there was enough capacity in the United States to meet the rising demand for endoscopic screening, called the Survey of Endoscopic Capacity (SECAP I). The survey found that there was capacity to screen United States residents using fecal occult blood tests with follow-up colonoscopies, but not using colonoscopy as the first-step screening test. In 2011, the Centers for Disease Control and Prevention commissioned SECAP II as a follow up study to determine the colorectal cancer screening capacity in the nation and in additional selected states, including Alaska.[121] This study collected data on the current number of flexible sigmoidoscopy and colonoscopy procedures performed each year, as well as the additional number of procedures (unused capacity) that could be performed each year. A forecasting model was developed based on the demographic characteristics of the population in the state and the number of screenings that need to be completed among the eligible population. The study found that current capacity in Alaska is not adequate to meet the use of screening tests based on the current pattern of screening test use (primarily colonoscopy).[73]

A further issue is whether colonoscopy is being performed more frequently than national guidelines would suggest, leading to increased social and financial costs. Several nationally representative studies of physicians who perform colonoscopy have found that more frequent surveillance intervals for asymptomatic average-risk patients, or older patients, than national recommendations is common, particularly for hyperplastic polyps and low-risk lesions such as small adenomas, which has further implications for overall screening capacity nationwide.[122, 123]

Alaska Native Colorectal Cancer Screening Trends

Screening rates among the Alaska Native population are lower than U.S. White rates, but have been steadily increasing, from 29% in 2000 to 58% of age-appropriate Alaska

Native people being up to date with colorectal cancer screening (colonoscopy in last 10 years or flexible sigmoidoscopy in last 5 years) in 2012 (Alaska Tribal Health System (ATHS) Government Results and Performance (GPRA) data, 2000-2012). Data from the Alaska Behavioral Risk Factor Surveillance System (BRFSS) in 2011 showed that 68.1% of Alaska Native adults reported ever had a sigmoidoscopy or colonoscopy, which was an increase from 50% in 2010 and 51.8% in 2008. The 2011 rate is the first time that the Alaska Native rate has been above the rate for all Alaskans (65%) and Alaska Whites (65%).[124] Despite substantial efforts, colorectal cancer screening rates among Alaska Native people fall short of the Healthy People 2020 target and the Centers for Disease Control and Prevention National Colorectal Cancer Control Program goal. Additionally, Alaska Native screening rates vary widely by geographic region, from 33% to 72% statewide in 2012.[125] The continuing large disparities in colorectal cancer mortality and incidence between Alaska Native people and U.S Whites suggest that screening for colorectal cancer needs significant improvement.

International Incidence, Mortality, Screening Methods, Intervals, and Rates

Rates of colorectal cancer vary by country, with Australia/New Zealand, Western Europe and North America experiencing the highest incidence of the disease, and African nations the lowest. Similarly, colorectal cancer mortality is highest in Central and Eastern Europe, and lowest in African nations.[126] Incidence has been increasing worldwide; colorectal cancer is the third most commonly diagnosed cancer in men and second in women. In contrast to the declining mortality seen in the United States, colorectal cancer mortality has been increasing worldwide, especially in rapidly developing countries such as South America, Eastern Europe, and East Asia, which may be related to the increasing adoption of Western dietary and lifestyle practices.[126]

Countries have differing recommendations for screening methods and follow-up intervals.[127, 128] Partly this is a reflection of limited resources and more pressing health priorities in low- and very-low income countries. But variations are also found among

higher income countries. For example while Poland, Germany and Austria screen the entire average-risk population via colonoscopy, generally after age 60, Italy provides flexible sigmoidoscopy as the primary screening test. Most countries, however, focus on annual or biennial guaiac-based fecal occult blood tests or immunochemical fecal occult blood tests, and only provide colonoscopies for higher-risk patients and diagnostic follow-up.[126] Countries also vary as to screening age to begin guaiac-based fecal occult blood tests or immunochemical fecal occult blood tests. For example, the Australian National Bowel Screening Program currently provides a iFOBT only at ages 50, 55, and 65.[126] One of the most important issues involved in setting up national screening programs is that colorectal cancer screening should only be promoted in settings in which appropriate follow-up and treatment are available.[129] Worldwide, colorectal cancer screening remains below 50%, even in countries with national colorectal cancer screening programs. However, some individuals in those countries may be obtaining screening through providers outside the national screening program, but it is not known to what extent this occurs.[126]

Risk Factors for Colorectal Cancer

There are many known factors that increase or decrease the risk of colorectal cancer. Major risk factors for colorectal cancer include both modifiable lifestyle risk and protective factors and non-modifiable factors like age and family history (see Figure 1-9).[4]

	Relative Risk
Factors that increase risk:	
Heredity and Medical History	
Family history	
1 first-degree relative	2.2
More than 1 relative	4.0
Relative with diagnosis before age 45	3.9
Inflammatory bowel disease	
Crohn disease (colon)	2.6
Ulcerative colitis	
Colon	2.8
Rectum	1.9
Diabetes	1.2
Other Factors	
Obesity	1.2
Red meat consumption	1.2
Processed meat consumption	1.2
Smoking	1.2
Alcohol consumption	1.1
Factors that decease risk	
Physical activity (colon)	
Men	0.8
Women	0.7
Calcium	0.8
Milk consumption	0.9

Figure 1-9. Summary of major risk factors for colorectal cancer.[4]

Modifiable Risk Factors

Modifiable factors that are associated with an increased risk of colorectal cancer include physical inactivity, obesity, high consumption of red or processed meats and low consumption of fruits and vegetables, tobacco use, and moderate-to-heavy alcohol consumption.[2, 4, 130-134] Protective factors that may decrease the risk of colorectal cancer include aspirin and non-steroidal anti-inflammatory drugs, multivitamin use (including supplemental folic acid and calcium, and physical activity, which may decrease the risk of colorectal cancer by as much as 50%.[2, 135] A Danish prospective cohort study found that 25% of colorectal cancer cases could be avoided by maintaining a healthy abdominal

weight, being physical active at least 30 minutes per day, eating a healthy diet, not smoking, and not drinking excessive amount of alcohol.[136]

Non-modifiable Risk Factors

The lifetime risk of being diagnosed with cancer of the colon or rectum is about 5% for both men and women in the United States. Both colorectal cancer incidence and death rates increase with age; about 90% of new cases and 94% of deaths occur in those aged 50 and older.[4] From birth to age 39 the probability of developing invasive colorectal cancer is 1 in 1,212 in men and 1 in 1,236 in women. Among those aged 40 to 59 the rates go up considerably to 1 in 106 in men and 1 in 134 in women; among those aged 60 to 69 the rates are 1 in 71 for men and 1 in 102 for women; at age 70 and older the rates are 1 in 24 for men and 1 in 26 for women.[7] The median age at diagnosis in the United States is 68 years in men and 72 years in women. Overall, rates of colorectal cancer for men are about 35% to 40% higher than for women. A personal history of colorectal polyps or cancer is associated with developing new colorectal cancers, especially if diagnosed at a younger age. Inflammatory bowel disease (IBD), which includes ulcerative colitis and Crohn's disease, and type 2 diabetes mellitus are likewise associated with a higher risk for developing colorectal cancer.[4]

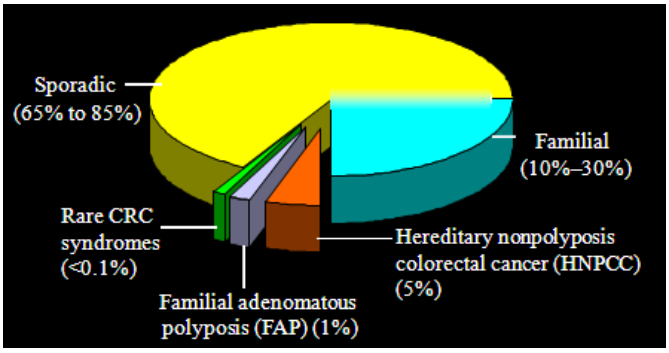


Figure 1-10. Causes of hereditary susceptibility to colorectal cancer.[137]

As shown in Figure 1-10, the majority of colorectal cancers (65% to 85%) occur in persons with no known cause (i.e., they are considered sporadic). A total of 10% to 30%

of cases of colorectal cancer occur in people who have a family member who has had an adenomatous polyp or colorectal cancer. This family history may increase colorectal cancer risk by influencing adenoma formation or enhancing the formation of new lesions.[138] A small percentage of colorectal cancers occur as part of an inherited syndrome. Approximately 5% are associated with Lynch syndrome (also known as hereditary nonpolyposis colorectal cancer or HNPCC) and about 1% are associated with familial adenomatous polyposis (FAP). These hereditary conditions cause rapid adenoma to carcinoma progression or multiple polyps and carcinoma progression.[4] HNPCC is a result of germ line mutations in DNA-mismatch repair (MMR) genes, which can be inherited from either parent. Tumors with defective MMR are characterized by the presence of a particular tumor phenotype, termed microsatellite instability (MSI).[139] Persons with these inherited syndromes have a propensity to develop other tumor types in addition to colorectal cancer, including tumors of the endometrial, ovarian, gastric, small intestine, brain, ureter, and biliary tract.[140] Less than 0.1% are rare colorectal cancer syndromes. It is important to note that there is no well-defined threshold between sporadic and familial colorectal cancer at this time, and there are likely to be multiple low penetrant genes plus environmental factors at work in the pathogenesis of colorectal cancer.[141, 142]

Alaska Native Risk Factors

The Education and Research Towards Health (EARTH) Study (2004-2006) collected chronic disease risk factor data for Alaska Native people in three regions of Alaska (southcentral, southwest, and southeast) which provide some baseline information on colorectal cancer risk factors among this population. Alaska Native people have many of the same colorectal cancer risk factors as the general United States population. Current cigarette use among Alaska EARTH Study participants (n=3821) was twice the prevalence of the Healthy People 2010 (HP 2010) goal (32% vs. 12%) and current smokeless tobacco (ST) (both commercial and homemade) use was markedly higher: 18% vs. 0.4%. About a quarter (24%) of study respondents were former smokers or

former ST users (18%) and likely to still be at risk.[143] Alaska Behavioral Risk Factor Surveillance System (BRFSS) data show that the percent of current smokers and ST users among Alaska Native adults is two-fold or greater than among Alaska non-Native people.[143, 144]

Overweight and obesity were likewise high among Alaska EARTH Study participants. Based on standard categorization of Body Mass Index (weight in kilograms divided by height in meters squared), 42% of participants meet the definition of obesity (BMI ≥30.0), and 32% were overweight (BMI 25.0 to 25.9). Only one quarter of the study population fell in the recommended range for healthy weight and the prevalence of obesity among Alaska EARTH study participants exceeded the rate among Alaska non-Native BRFSS respondents (42% vs. 25%).[143] Self-reported fruit consumption (2+ servings per day) was about half of HP2010 recommendations (38% vs. 75%) and vegetable consumption (3+ servings per day) was likewise lower: only 45% of men and 52% met the goal.[143] The 2009 Alaska Behavioral Risk Factor Surveillance Survey (BRFSS) likewise reported similar findings; only 14% of Alaska Native people reported eating five or more servings of fruits and vegetables per day, compared to 25% reported by Alaska non-Native people.[144]

Self-reported physical inactivity was also high among Alaska EARTH Study participants; only 35% of women and 61% of men reported getting five or more hours of moderate and vigorous physical activity. Similarly, Alaska BRFSS data showed that 17% of Alaska Native men and women combined met the goal of moderate and vigorous activity as defined as moderate activity on 30 or more minutes per day on five or more days per week or vigorous physical activity for 20 min or more per day, for three or more days per week. This is in comparison with 27% of non-Native Alaska residents who met the goal.[143]

Findings from the Alaska EARTH Study and others have reported on the shift in Alaska Native diet from wild to store-bought foods, and decreases in overall physical activity as well as increasing availability and use of motorized vehicles for hunting and subsistence activities.[69, 145-149] These trends, along with other colorectal cancer risk factors and the aging of the population, will likely continue to contribute to increases in colorectal cancer incidence.[150] Although these risk factors are shared with other United States populations, additional genetic mutations which might predispose Alaska Native people to colorectal cancer have been postulated due to the increased rates of colorectal cancer, especially among Alaska Native women, and the larger proportion of tumors in the proximal colon and tumors of higher grade and severity among Alaska Native colorectal cancer patients.[139] However, hereditary risk factors like HNPCC do not seem to be unusually high in Alaska Native people.[14] Furthermore, a study by Boardman et al. (2007) looked at evidence of defective DNA mismatch repair (MMR) by testing tumors from colorectal cancers from Alaska Native people for altered protein expression (hMLH1, hMSH2, and hMSH6) and for the presence of microsatellite instability (MSI).[139] Their study did not find evidence of an association between tumor stage and MMR status, although they did find that colorectal cancers with defective MMR were more frequently seen in the proximal colon and among patients presenting at a young age. Overall evidence of defective DNA MMR was found in 14% of the colorectal cancers tested, a frequency similar to that reported in other population groups.[139] Although further research is needed to evaluate possible genetic risk factors among Alaska Native people, it is likely that increases in body weight, dietary changes, increases in physical inactivity, and tobacco use, are strong contributing factors to colorectal cancer in Alaska Native people, similarly to what has been described in other United States populations.[134]

Family History

Family history is a critical component of colorectal cancer risk stratification.[151-153] The overall lifetime risk of colorectal cancer in the U.S. is approximately 6%. Persons with a history of colorectal cancer or adenomatous polyps in one or more first-degree relatives

(FDRs: parents, siblings, or children) are at increased risk. Studies of FDRs of colorectal cancer patients in the prospective cohort Nurses' Health Study and the Health Professionals Follow-up Study found that FDRs had a 1.7-fold increase in risk of colorectal cancer. Furthermore, for persons who had two or more affected first-degree relatives or who were younger than age 44 the relative risk (RR) increased substantially. This association held even after adjustment for other known or suspected risk factors for colorectal cancer.[154] Data from the National Polyp Study which calculated the relative risk of colorectal cancer in FDRs compared with spouse controls confirms these findings; FDRs are over twice as likely to experience colorectal cancer (relative risk=2.2), especially if their family member was affected before age 45 (relative risk=3.9).[154-157] If the person has one affected FDR the risk is 2-3 fold higher (lifetime risk 12-18%). If a person has two FDRs with colorectal cancer or if the FDR was less than age 50 the risk is 3-4 fold (18-24%). Even having second- and third-degree relatives with colorectal cancer can increase the risk of colorectal cancer to a lifetime risk of 9%.[76, 156] Furthermore, the presence of advanced adenomas (not colorectal cancer) in a FDR is a risk factor for colorectal cancer development in their close family members.[157, 158]

There may also be a synergistic effect increasing the risk for colorectal cancer between modifiable risk factors such as diet, alcohol and tobacco use, and having a family history of the disease.[159] Data from two large cohort studies, the Nurses' Health Study and Health Professionals Follow-Up Study, found that the previously reported association between heavy alcohol consumption (more than 30 grams per day) and colorectal cancer differs by family history; participants with a family history who consumed alcohol had a higher incidence of colorectal cancer than those with no family history.[160] One study found that family history increases the risk of sporadic colorectal cancer in men mainly through its interaction with lifestyle exposures, including high beef and alcohol intake.[141] FDRs of colorectal cancer patients are the largest groups of individuals at increased colorectal cancer risk. Overall, it is believed that screening strategies targeting FDRs of affected

cases could contribute to the prevention or early detection of 15% to 20% of colorectal cancers.[158, 161]

Recommended Screening Methods and Intervals

Although the field of molecular epidemiology and genomics is rapidly expanding the potential for identifying persons at risk of colorectal cancer; including the discovery of new biomarkers, whole genome association studies (GWAs), and expression profiling and proteomics;[162-165] family history is still one of the most valuable tools which provides predictive value to identify individual patients at increased risk of colorectal cancer.[166] In the early 2000s a number of screening recommendations existed for FDRs, which varied on the definition of risk type and frequency of tests recommended, and the age at which FDRs should start screening.[167-170] However, since then, as the evidence base has grown regarding the increased risk for colorectal cancer among this population, recommendations have solidified in favor of early screening (pre-age 50) using colonoscopy as the recommended screening method. Screening guidelines vary slightly by professional medical groups, but in general, United States national guidelines recommend that persons with a family history of colorectal cancer (one FDR or two or more second-degree relatives) undergo cancer screening by colonoscopy beginning at age 40 or 10 year younger than the age at diagnosis of the youngest affected relative, whichever is earlier. FDR screening should occur every five years for normal exams, and more frequently if findings are present.[55, 171] The Alaska Native Medical Center (ANMC) has further guidelines that if there are documented adenomatous polyps in a FDR or multiple second-degree relatives then those persons should be screened with colonoscopy starting at age 50 continuing every five years, or more frequently if findings are present (Alaska Area Native Health Service CRC Screening Guidelines, revised June, 2008).

Predictors of Family History Screening Adherence

Healthcare professionals in the United States have long used family history information collected from individuals as a risk assessment tool.[172] However, family histories are

rarely used to identify and provide systematic outreach to those at increased risk for disease, especially for colorectal cancer,[173] and studies have shown that documentation of family cancer history in medical records is inconsistent, and lacking in over half of primary care patients.[174-178] Incorporating family history into clinical practice is challenging due to the lack of standardized methods for collection and reporting of family history.[179] There is also a dearth of information on the extent to which clinicians use family history information to drive discussions and provide recommendations to their increased risk patients, although it has been found that those with a family history are more likely to report healthcare provider recommendation to undergo screening.[180] Studies of physician knowledge and practice patterns have found that many providers are not aware of the recommended guidelines regarding screening intervals for FDRs or provide notification to their at-risk patients.[181] For the most part, when used, these FDR screening referral decisions are based on self-reported pedigree information. Several studies have compared self-reported history of colorectal cancer among patients with medical record data. While some studies found that FDR-reported colorectal cancer family history is fairly accurate and may be relied upon for colorectal cancer risk assessment, other studies have found underreporting of family history.[182-185] One study reported that 25% of FDRs did not know that their parent or sibling had histologically confirmed diagnoses of colorectal cancer.[186] In general, FDRs are less likely to be aware of early stage (*in situ* or localized) colorectal cancers among their family members than later stage or more severe colorectal cancers.[186]

Despite the number of published recommendations for screening individuals at increased risk of CR colorectal cancer due to their family history, a review by Rees et al. (2008) found few studies that had specifically investigated screening adherence in this population, and none had assessed FDR patient preference as a factor in screening adherence.[167] The studies that exist have found that many of the demographic and behavioral factors that influence screening adherence among the average risk population also influence colorectal cancer screening by FDRs of colorectal cancer patients. One

study reported that FDR barriers included lack of awareness of colorectal cancer and the need for screening, concerns about concerns about efficacy of screening tests, fear of finding cancer, embarrassment and lack of provider recommendation.[93] Additionally, sociodemographic factors including income, education and insurance status also play a role in screening adherence by FDRs. However, reported associations have been inconsistent among studies. For example, some studies reported higher screening uptake among older FDRs,[177, 187, 188] while other studies reported that younger cohorts were more likely to obtain screening by colonoscopy than older cohorts,[189] and others reported no association between age and screening behavior.[190] Similar inconsistencies have been found among sex, educational level and income and FDR screening adherence.[167, 191] However, similarly to the general population, provider recommendation and awareness of the benefits of screening have been found across studies of FDRs to be positively associated with screening adherence.[93, 177, 180, 187, 192, 193]

Family-related factors have been associated with increased screening by FDRs, including the number and proportion of affected FDRs in the family.[177, 187, 194] Additionally, some studies found that family support and sibling closeness were significantly associated with screening adherence by siblings of affected colorectal cancer cases.[111] Knowledge of risk for family members by the colorectal cancer patient might also be important for screening among their FDRs. In one study, FDR screening colonoscopy adherence was significantly higher (27%) when the colorectal cancer patients were aware of the increased risk for their family members in contrast to screening adherence among siblings of colorectal cancer patients who were not aware of the risk (20%).The authors conclude that informing colorectal cancer patients about the potential risk for their relatives may increase participation in screening by those family members.[195]

Of note, these studies have shown that perceived risk for colorectal cancer is not necessarily associated with receipt of recommended colorectal cancer screening by FDRs,[93, 109, 191] as shown by a quote from a focus group of African American women:

"When my sister died, we agreed we would go get tested. So far only one of us has, and there are five of us. I guess I have a fear they'll find something."[196] However, other studies have shown greater screening receipt by those with a family history compared to those without a family history.[180, 197] Of note, one study found that 84% of FDRs were interested in having a genetic test if one were available; although only 59% of the FDRs in the study were adherent to current colorectal cancer screening guidelines.[198] A difficulty with the FDR screening adherence literature is that many of the earlier studies included fecal occult blood test, sigmoidoscopy and colonoscopy as screening options, and so less is known about screening adherence to colonoscopy specifically, starting at least at age 40 and continuing every five years, which presents greater demands upon patients for completion than other screening methods. To date no studies have been published on predictors of screening adherence among Alaska Native FDRs.

Screening Prevalence among First-degree Relatives

It is difficult to get a true screening prevalence among FDRs as many studies in the 1990s and early 2000s only used fecal occult blood test or sigmoidoscopy as a screening outcome measure, which are not currently recommended for screening this increased-risk population. Data reported from the 2000 U.S. National Health Interview Survey showed that of individuals with a positive family history, only 28% of Whites and 9% of African Americans had been screened by endoscopy. This racial disparity persisted even after adjustment for age, gender, educational level, insurance status, and usual source of care.[199] Another study a few years later in 2002 reported a screening adherence rate of 57% among siblings of colorectal cancer patients,[111] and a cross sectional study in 1995 of twin sisters found that 69% of the cotwins reported receiving a sigmoidoscopy, compared with 27% of the general population, although none of the cotwins in the study reported receiving a colonoscopy.[190]

United States screening rates among FDRs have increased over the past decade: the 2005 National Health Interview Survey found that reported colorectal cancer screening

(endoscopy) had increased to 65% of those with a known family history. However, 13% reported being screened by fecal occult blood test, which is not considered adequate for screening this increased risk population.[105] Additionally, only participants over age 50 were asked their screening history, which may over represent the true screening rate among FDRs, many of whom need to be screened at much earlier ages. Results vary among other countries. A Canadian study published in 2009 found that 60% of FDRs were adherent to current screening guidelines.[106] An Australian study by Ryan et al. (2013) found that 69% of FDRs had ever received any colorectal cancer testing (i.e. FOBT, sigmoidoscopy or colonoscopy), although only 25% of 'slightly above risk" (1 FDR with colorectal cancer diagnosed age 55 or older), 47% of those at "moderately increased risk" (1 or more FDR with colorectal cancer diagnosed before age 55), and 49% of "potentially high risk" FDRs (FAP, HNPCC, or colorectal cancer before the age of 50) were up-to-date with screening according to Australian guideline recommendations (biennial fecal occult blood test for 'slightly above risk' and colonoscopy every five years for 'moderately' and 'high risk').[200] This is in contrast with a 1997 study in New South Wales, Australia, which found only 1% of FDRs were screened in accordance with Australian recommendations at the time.[201] Another study from Spain (2007) found low screening adherence among FDRs, with only 38% screened for colorectal cancer.[202] However, a study from Italy that used an educational intervention (letters, phone calls, face-to-face interactions) was able to increase colonoscopy use among FDRs ages 45-75 to 78% compared with the control group population rate of 8%.[194] In summary, the available evidence suggests that screening rates of FDRs of colorectal cancer patients in accordance with guideline recommendations is increasing but remain much lower than would be optimal to reduce colorectal cancer incidence and mortality on a population level.

Screening Prevalence among Alaska Native First-degree Relatives

Because of the overall disproportionate colorectal cancer incidence and mortality rates among Alaska Native people, it is important to identify those at highest risk and

encourage them to receive appropriate screening.[16] Although no Alaska BRFSS data are available on family history of colorectal cancer, data from a supplemental questionnaire included in the 2008 Oregon BRFSS found that 8% of respondents had a FDR with colorectal cancer.[180] In Alaska, the only published data available on Alaska Native family history of colorectal cancer comes from the Alaska Education and Research Towards Health (EARTH) Study, which found 13% of Alaska EARTH Study participants (2004-2006) reported one or more FDRs diagnosed with colorectal cancer before age 50.[143] Of those who knew the age of diagnosis of their relative, 38% reported that their family member was diagnosed with colorectal cancer before age 50.[203] Study participants who reported a family history of colorectal cancer were twice as likely to report receipt of a colonoscopy or flexible sigmoidoscopy in the past five years (44.1% vs. 26.2%).[204] However, this still represents a low screening rate for a population at increased risk.

Evidence Base for Colorectal Cancer Prevention

Systematic evidence-based reviews by the U.S. Community Preventive Services Task Force outlined in the Guide to Community Preventive Services have identified effective public health strategies that support increased colorectal cancer screening.[205] Currently, the Community Guide has found sufficient to strong evidence to recommend small media (such as brochures with tailored messages targeted to specific under-screened minority groups), client reminders (such as post cards, phone calls, or reminders at the point of care), one-on-one education, provider reminder systems, including office-based systems,[206] provider assessment and feedback, and the reduction of structural barriers (such as those associated with procedure access, scheduling, or transportation) as effective strategies for increasing colorectal cancer screening. It is important to note that these strategies are often recommended to be used to increase use of flexible sigmoidoscopy and colonoscopy for colorectal cancer screening, even though the evidence base comes from studies which only used fecal occult blood tests as the screening modality. Interventions that use newer colorectal cancer screening methods, such as fecal immunochemical tests and stool DNA tests, have not yet been evaluated and

it is unknown whether effects differ for these tests.[207] The Task Force found that there was insufficient evidence for the use of mass media, client incentives, group education, and reducing client out-of-pocket expenses to increase colorectal cancer screening in their October, 2009 assessment.[208, 209]

The Community Guide recommended interventions for cancer screening are based on review of the published literature and where available, National Cancer Institute (NCI) research-tested intervention programs. There is a growing body of literature around colorectal cancer screening interventions, but much is still unknown, especially for interventions that promote endoscopy (flexible sigmoidoscopy and colonoscopy) as screening modalities. The Task Force notes in their reviews that absence of evidence or insufficient evidence is not indicative that a specific program or intervention does not work; rather that the overall evidence base is not strong enough or more information is needed to make recommendations about intervention benefits, particularly where there is a dearth of research studies, for example for reducing client out-of-pocket expenses, where no colorectal cancer screening research studies were found by the Task Force using this type of intervention.[207, 210] It can be especially challenging to evaluate the effectiveness of multi-component programs, especially ones that use broad population-based strategies, although the Task Force did find some evidence that implementing a multicomponent intervention can provide incremental benefits. The Task Force cautioned against implementing multicomponent interventions when there are not adequate resources and infrastructure to deliver all components with fidelity.[208]

One form of educational media not addressed by the Community Guide is interactive exhibits. Such exhibits have been increasingly used by general and science museums to promote public participation and engagement.[211] However, limited data exists on the extent to which interactive exhibits leads to greater understanding among the public. The studies that have been done have primarily examined how people interact with the exhibits,[212] not whether interaction with exhibits lead to knowledge and behavior change.

A few studies have been conducted on special events as tools for behavior change, such as health fairs, community celebrations, educational parties, and Readers' theatre. These special events promoting increased access to health services and cancer screening include breast health educational parties, where use of breast health knowledge games led to increased screening among underserved and uninsured women in New Jersey;[213] a project which provided limousine service to and from screenings to encourage mammography use;[214] as well as cultural events ('Ohana Day Project in Hawaii)[215] and more traditional health fair events to promote awareness and increase knowledge.[216, 217] In Alaska, a colorectal cancer-focused script was developed for use in Alaska Native communities as Readers' theatre, a community event in which participants read aloud from a non-memorized script. Use of the Readers' theatre script was shown to increase comfort with cancer screening and interest in making health changes among theatre participants, and a giant inflatable colon was used to promote colorectal cancer screening knowledge, intention to get screened, and comfort talking about screening with friends and family among community members statewide.[218, 219]

Less is known about the effectiveness of interventions targeting systems-level changes in healthcare systems, such as in primary care settings, but these might also be an effective method to improve colorectal cancer screening and follow-up.[207, 220] For example, from 2005 to 2009, Kaiser Northern California doubled its up-to-date colorectal cancer screening from 35% to 69% among commercially insured enrollees and increased screening for Medicare enrollees from 46% to 75% by implementing a highly organized screening program.[221] Other recommendations to increase colorectal cancer screening are for state health departments to design systems that allow linkage of Medicaid enrollee data to other datasets, if such linkages are allowed. This would enable identification and active recruitment for screening, and develop program registries to monitor participation, diagnostic follow-up, treatment initiation and long-term outcomes.[9] Overall, it is important to consider the characteristics of the priority population carefully, including

what factors impact their screening behaviors when determining which type of interventions to initiate to promote colorectal cancer screening.

Centers for Disease Control and Prevention (CDC) Social Ecological Model

In order to understand the myriad factors that influence an individual's likelihood of obtaining colorectal cancer screening it is helpful to visualize these factors in the context of a model. There has been a growing understanding that many public health challenges are too complex to be understood adequately from single levels of analysis, and instead, require more comprehensive approaches that integrate interpersonal, organizational, community planning, and regulatory perspectives.[222] This has led to the development of several perspectives on health promotion, including social ecological analyses of health promotion. The social ecological model of health promotion is a systems model with multiple bands of influence and the individual at the core.[223-225] The model assumes that appropriate changes in the social environment will produce changes in individuals and that the support of individuals in the population is essential for implementing environmental changes.[226, 227]

The Centers for Disease Control and Prevention has adapted the social ecological model to represent a multi-level systems approach to colorectal cancer prevention, and suggest the range of potential types of screening promotion activities (see Figure 1-11).[223] At the core of the model is the individual, surrounded by four other bands of influence representing the interpersonal, organizational, community, and policy levels. The second band represents the most immediate influence on the individual-family and healthcare professionals (Interpersonal Level). Studies have shown that health provider recommendation is consistently one of the pivotal reasons for why people chose to get screened.[102, 228-230] The third band is the Organizational Level, which includes healthcare systems, health departments, and professional organizations that aim to facilitate individual behavior change through organizational systems and policies. The fourth band represents the Community Level, and represents activities that occur at the community

level, often by institutions such as comprehensive cancer control coalitions, tribal health departments, media, and community advocacy groups. The final band represents the Policy Level, which seeks to influence the individual indirectly through systems and policy changes at the local, state, and federal level.

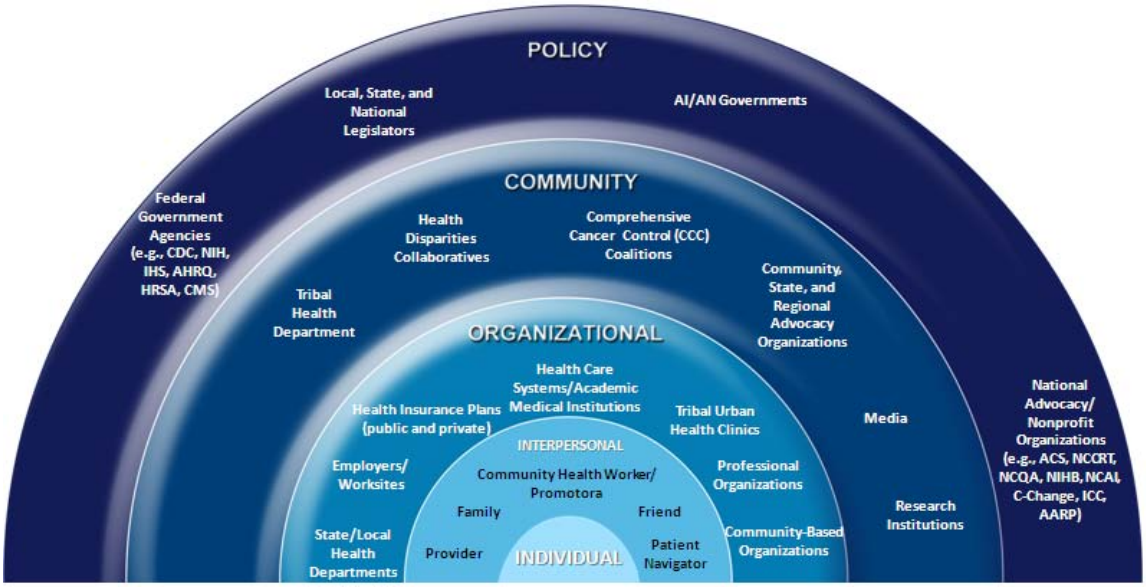


Figure 1-11: Centers for Disease Control and Prevention Social Ecological Model (SEM)[225]

The social ecological model is broad, and as such can be applied to colorectal cancer screening interventions among Alaska Native populations. Most interventions to promote colorectal cancer screening among Alaska Native people have occurred at the Interpersonal and Organizational levels. This has played to two key strengths, namely, the importance of family and community in Alaska Native culture, and the ability of regional tribal health organizations to make direct changes to promote screening among the populations that they serve. The band of the social ecological model that is not as easily influenced in the Alaska Native colorectal cancer screening context is the Policy Level, as this often involves state and federal policy changes, such as requirements for increased financial coverage for colorectal cancer screening by insurance companies. These do not appear to factor into Alaska Native individual decision making on colorectal cancer screening as much as other forms of influence such as family and

healthcare providers, including affiliated healthcare staff like case managers and patient navigators.

However, policy changes can be made at the regional tribal health organization level, which would have beneficial impacts on patient screening outcomes. This can be illustrated more generally by another model which focuses specifically on the primary care setting, which represents elements of both the Organizational and Interpersonal level (see Figure 1-12 below). This model outlines leverage points for increasing colorectal cancer screening in primary care practices.

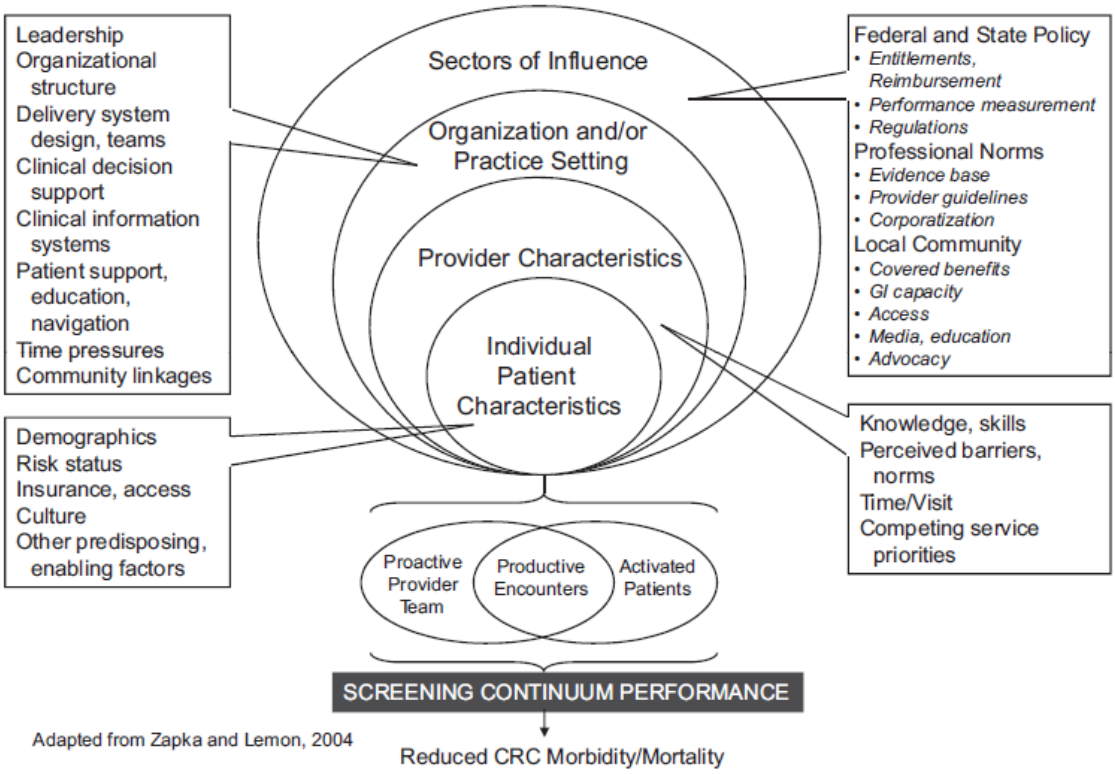


Figure 1-12. Factors affecting improved CRC screening in primary care.[231]

Patient Navigation

One type of intervention recommended by the Community Guide for increasing colorectal cancer screening is one-on-one education with the goal of informing,

encouraging and motivating patients to seek recommended screening.[205] These messages can be delivered by a variety of healthcare workers or other health professionals, lay health advisors, such as promotoras or even volunteers. To this end, there has been an increase over the last two decades in the use of patient navigation for colorectal cancer screening.[232, 233] Patient navigation is a way to improve effectiveness of care and increase screening rates, especially among low-income, minority, and medically underserved populations.[196, 234-236] Patient navigators have a multitude of backgrounds, from lay community members, to community health workers, to case managers and nurses. The job duties, education, and experience required for these positions often vary widely by location and organization. colorectal cancer screening patient navigation provides individualized assistance to help overcome healthcare system and patient-level barriers to care and helps guide individuals into action by getting needed cancer screening.[196, 232, 237] Outreach is usually conducted by sending mailed reminder letters and phone calls to patients or community members encouraging them to get colorectal cancer screening, as well as face-to-face approaches.[233] These approaches are often accompanied by the use of small media (e.g., brochures) as well as client reminders and follow-up to complete screening. Patient navigators are also increasingly being seen as key for managing referrals, helping patients navigate the healthcare system, and facilitating follow up surveillance of abnormal screening, such as adenomatous polyp surveillance.[4, 234, 236]

The benefits of patient navigation in improving client screening adherence has been studied in several populations, although there had not been many studies of the overall economic effect of using patient navigators in the colorectal cancer screening context. One such study that examined use of patient navigators to increase colonoscopy volume and completion rates in an urban public hospital system found the patient navigator program cost-effective and yielded a net financial benefit, although cost analysis has not been studied more widely to determine net benefit among other types of healthcare organizations and settings.[238] Although use of the patient navigation model for increasing colorectal cancer screening among the general population has been on the rise, there has

been little or no use of patient navigation for focused outreach to patients at increased risk of colorectal cancer such as to those with a family history of the disease. Patient navigation has been identified as a key component for increasing colorectal cancer screening in general among Alaska Native people,[26] and is currently being used for targeted outreach to first-degree relatives of colorectal cancer patients.[72]

National Policy Related to Colorectal Cancer Screening

On March 23, 2010, Congress passed and the President signed the Affordable Care Act (ACA), healthcare reform legislation giving greater access to colorectal cancer screening through a requirement for private health insurers to cover recommended preventive services without any patient cost sharing such as copays and deductibles. As of September 23, 2010, all new private health plans are required to cover colorectal cancer screening tests with a U.S. Preventive Services Task Force (USPSTF) rating of "A" or "B" without any out-of-pocket costs to patients. Currently, the USPSTF recommends screening for colorectal cancer using fecal occult blood testing, sigmoidoscopy, or colonoscopy in adults beginning at age 50 and continuing until age 75.

As of 2011, in the United States Medicare program, preventive services, such as colonoscopies, have no out-of-pocket costs and are exempt from deductibles. The deductible will be waived for colorectal cancer screening tests even when polyps are detected and removed. Additionally, starting 2013, states will be given a one percent increase in the Federal Medical Assistance Percentages for Preventive Services if they offer Medicaid beneficiaries all preventive services recommended by the USPSTF, offer immunizations recommended by the Advisory Committee on Immunization Practices, and remove cost sharing for all these services.[4] This is important as patients can encounter unexpected cost sharing for screening colonoscopy. This occurs under three different circumstances: 1) when a polyp is detected and removed during a screening colonoscopy; 2) when a colonoscopy is performed as part of a two-step screening process following a positive stool blood test; and 3) when the individual is at increased risk for

colorectal cancer due to family or personal history and may receive earlier or more frequent screening compared with average risk adults. One study conducted in 2012 by the Henry J. Kaiser Family Foundation, the American Cancer Society, and the National Colorectal Cancer Roundtable collected interview data in eight states to determine how private insurers were approaching cost sharing for colorectal cancer screening. The study found that cost sharing varies widely based on those three circumstances depending on the insurer and how physicians code the colonoscopy procedure. Consumer complaints on unexpected colorectal cancer screening cost sharing have led to additional state-level legislation to clarify the intent of ACA.[239]

Recent history shows that as colonoscopy becomes a covered procedure for screening, use by beneficiaries increases. For example, screening by colonoscopy increased rapidly following implementation by the Medicare program in 2001 of coverage for colorectal cancer screening colonoscopy for average-risk enrollees.[118] Therefore, if present trends in screening preference continue and greater coverage is available from insurance plans, it can be projected that screening by colonoscopy will increase nationwide, unless other screening methods are developed as alternatives, such as stool DNA testing.

Alaska Native Policy Related to Colorectal Cancer Screening

Even prior to ACA, the Alaska Tribal Health System (ATHS) had made colorectal cancer screening a priority, and colorectal cancer screening, including colonoscopy, is generally an entirely covered benefit for Alaska Native people receiving care at tribal health facilities statewide. Several regional tribal health organization Board of Directors have also made colorectal cancer screening a priority area. ANTHC passed an organizational level resolution in 2009 to support the development of projects and/or programs to increase colorectal cancer screening statewide (ANTHC Resolution 09-04). However, coverage of patient and escort travel costs are not always covered by regional tribal health organizations within the ATHS, which can result in significant cost sharing for Alaska Native people who have to travel from remote villages into hub communities or

into Anchorage to obtain colorectal cancer screening. There are currently practice guidelines for appropriate screening and follow up intervals for Alaska Native people (Alaska Area Native Health Service CRC Screening Guidelines, June 2008), but no Alaska Tribal Health System-wide guidelines for what portion of colorectal cancer screening (procedure, travel, escort travel) is covered by the healthcare system for Alaska Native people, which is left up to individual tribal health organizations to determine.

Alaska Native Tribal Health System

Alaska Native people are concerned about the increasing burden of cancer, which has led to a focus on cancer prevention within tribal health organizations statewide, collectively called the Alaska Tribal Health System (ATHS). As will be discussed in Chapter 3, the ATHS represents more than 140,000 Alaska Native and American Indian people through a number of federally recognized tribes and tribal health organizations. Each tribal organization retains its autonomy with regard to health priorities, services, and policies in their respective service areas. Formed in 1997, the Alaska Native Tribal Health Consortium (ANTHC) is a statewide non-profit health services organization owned and operated by Alaska Native people to provide health services to tribal members throughout Alaska and to support the THOs that comprise the ATHS. The ATHS is a hub and spoke network of small village-based clinics, sub-regional clinics, regional hospitals, and a large urban secondary and tertiary care facility (see Figure 1-13 below). The tribal village clinics are staffed by Community Health Aides/Practitioners (CHA/Ps), laypeople who are trained as first responders for emergencies and provide basic primary and preventive healthcare. Sub-regional clinics are staffed by CHA/Ps, physician assistants, and nurse practitioners. Regional hospitals provide inpatient, outpatient, and emergency services and are staffed by physician assistants, nurse practitioners, and physicians.[240] The ATHS comprises cradle-to-grave comprehensive care for eligible Alaska Native people. This integrated system of care has the potential for significant impact on colorectal cancer disease burden by allowing for a systematic focus on colorectal cancer prevention and control.

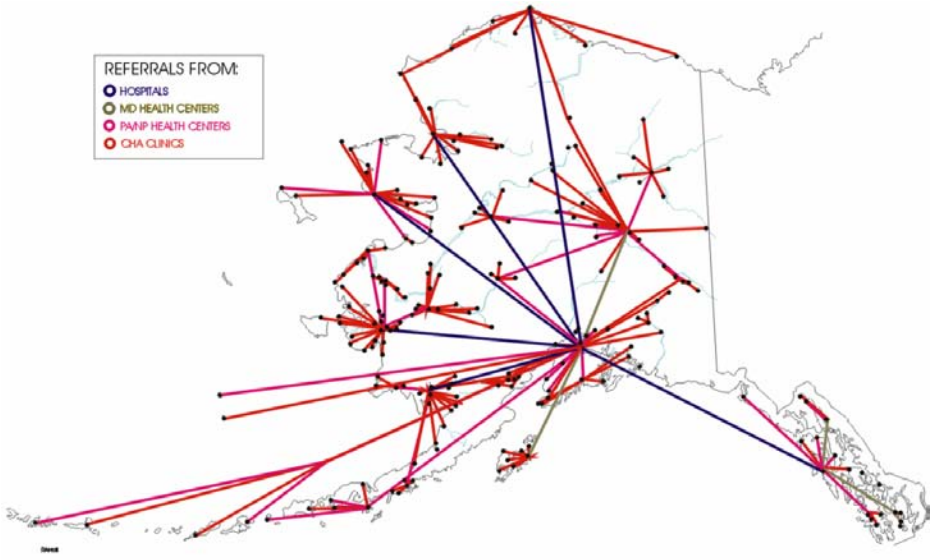


Figure 1-13. Alaska Tribal Health System referral patterns map.

Colorectal Cancer Prevention Efforts

Efforts to increase colorectal cancer screening rates in the ATHS have been undertaken by various tribal health organizations throughout Alaska. In the late 1990s, ANTHC began endoscopy training for nurse practitioners and physician assistants in order to improve access to screening flexible sigmoidoscopy and colonoscopy. Over the past decade, ANTHC has worked to improve colorectal cancer screening prevalence through various pilot projects and the creation of a Tribal Comprehensive Cancer Control Program. Some projects to reduce structural barriers in the Alaska Tribal Health System have included the development and implementation of a flexible sigmoidoscopy training program for rural mid-level providers; the provision of itinerant endoscopy services at rural tribal health facilities; the development and implementation of a colorectal cancer screening patient navigator project; the creation and use of a colorectal cancer first-degree relative database to identify and screen relatives of colorectal cancer patients; a study to test the specificity and sensitivity of immunochemical fecal occult blood test as a screening method, especially in *H. pylori* positive patients, and a study on the effectiveness of a screening method that detects colorectal cancer genetic molecular markers exfoliated in stool (sDNA test).[26, 72, 74] Along with these efforts state and tribal

health organizations have created multiple small media community health education tools, including brochures, posters, videos, health fair display boards, Readers' theatre scripts, and digital stories.[241] These tools are increasingly designed to be interactive and engaging and include multimedia components, such as theater events, personal stories, and videos.[218, 242, 243]

An internal review of medical records at the Alaska Native Medical Center (ANMC) in 1999 found that only 10% of the age-eligible Alaska Native population had been screened for colorectal cancer. To address this issue, the Alaska Native Medical Center Surgery Department trained a physician assistant to perform screening with flexible sigmoidoscopy. In 2000, colorectal cancer screening services were expanded by recruiting and training a nurse practitioner for a dedicated screening flexible sigmoidoscopy clinic. As a result of these combined efforts, the percentage of age-eligible Alaska Native people in the Anchorage area screened for colorectal cancer increased rapidly to 47% by December 2003, representing a five-fold increase.[244] Based on this success ANTHC developed a flexible sigmoidoscopy training program for nurse practitioners and physician assistants from regional hub communities across the state. The curriculum included didactic and clinical skills components. Seven providers were trained from 2005-2009 and as a result 205 rural patients received screening flexible sigmoidoscopies in that period. However, by the end of 2012 only one trainee continued to perform screening exams. Factors affecting attrition included staff turnover, competing clinical priorities, and a general shift to colonoscopy as the preferred screening modality for this increased-risk population.[74]

Because of the limited success of the flexible sigmoidoscopy training program, ANTHC shifted focus in 2007 to supporting itinerant screening colonoscopy field clinics. In this model an endoscopist from the Alaska Native Medical Center travels out to remote areas of Alaska to conduct three to five day colorectal cancer screening clinics at regional hospitals with clinical space available for endoscopy. Priority is given to patients who

have never been screened and to those individuals who have a family history of colorectal cancer or adenomatous polyps in one or more first-degree relatives. Patients in whom colorectal cancer is found are referred to Alaska Native Medical Center in Anchorage for further care. This model has shown greater success in getting patient screened, but is subject to issues including a lack of support staff at regional facilities, including trained sedation nurses, endoscopy technicians, and sterile processing technicians, and weather related travel delays, which can reduce a planned five day clinic to only two or three days of procedures when patients are unable to fly from their home community to the hub community where the screening clinics are being held. Despite these issues, this model is being used throughout the state for regions that do not have trained endoscopist staff on-site.[72]

In 2009, ANTHC was accepted as one of the three Alaska tribal grantees of the Centers for Disease Control and Prevention (CDC) National Colorectal Cancer Control Program.[26] As shown in Figure 1-14, ANTHC has six formal partner sites but provides technical assistance, including small media, training opportunities, and data request responses to an additional seven regional tribal health organizations. The goal of the ANTHC Colorectal Cancer Control Program (CRCCP) is to increase screening among Alaska Native and American Indian people through the provision of direct screening services, public outreach, provider education, and policy and systems improvements in the Alaska Tribal Health System. At the regional tribal health organizations with formal partnerships with the ANTHC CRCCP, Government Performance and Results Act (GPRA) data showed that screening rates increased by an average of 73% (range 4% to 177%) since the 2009 program initiation.

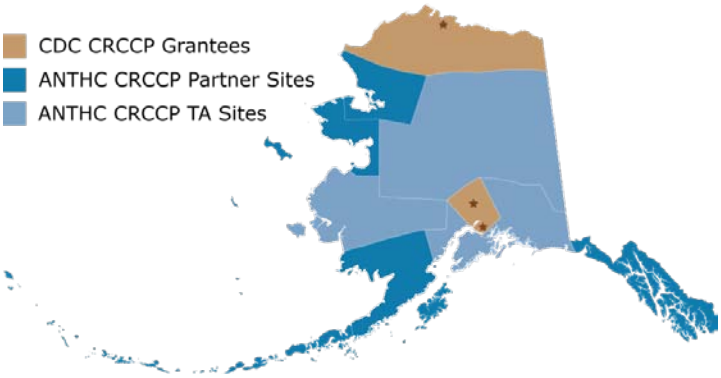


Figure 1-14. Alaska Native Tribal Health Consortium Colorectal Cancer Control Program (CRCCP) activities in Alaska.

Challenges for Colorectal Cancer Screening

There are a number of challenges to the delivery of colorectal cancer screening among Alaska Native populations. First, about 40% of Alaska Native people live in widely dispersed remote communities which are not connected by road. Most of these communities are only accessible year round by air, with seasonal access by boat or snowmobile. Endoscopy (colonoscopy and flexible sigmoidoscopy) services are available in Anchorage and at a few of the regional hospitals. Therefore, obtaining colorectal cancer screening for Alaska Native people residing in remote communities requires long distance, high cost air travel to access screening services, as well as overnight lodging in order to complete the colonic preparation prior to the screening procedure. It is important to note that because of the limited endoscopic capacity, the endoscopy that is performed is generally for symptomatic patients, not for screening. Additionally, the few regional physicians who are trained in endoscopy generally have competing clinical responsibilities and often limited support staff.[74] All of these factors have presented significant barriers to improving screening rates.

Furthermore, as elsewhere in the U.S.[121, 245] endoscopic capacity is limited in Alaska, particularly at the regional health facilities that serve the Alaska Native population. For many Alaska Native people living in remote communities, obtaining screening endoscopy requires travel to one of the seven regional health facilities with endoscopic

capacity or to Anchorage.[74] Due to a shortage of trained local personnel, only four of these regional facilities provide endoscopy on a continuous basis, while three hold intermittent screening clinics staffed by itinerant endoscopists.

A further challenge is the heterogeneous nature of the Alaska Tribal Health System, which includes multiple tribal groups with differing cultural traditions and histories. This heterogeneity makes it more difficult to draw conclusions as to best practices in promoting colorectal cancer screening among all Alaska Native men and women. However, previous ATHS studies have found that even if screening and/or travel for screening are financially covered, other barriers, such as systems level issues, still exist. Because of this the ATHS has increasingly focused on expanding patient navigation, education, and outreach efforts to ensure higher numbers of patients received recommended colorectal cancer screening.[72]

Colorectal Cancer Screening Research

Stool Test Studies

Additional research is needed to identify and test effective colorectal cancer screening among Alaska Native people. There are two major areas of research inquiry that exist for increasing colorectal cancer screening among the Alaska Native population, particularly for those living in rural regions of the state. The first is to expand the screening options available. The current recommendation of colonoscopy as the first line of screening for Alaska Native people presents challenges in the form of high cost to the Alaska Tribal Health System, higher risks for patients from surgical complications of colonoscopy, and the reluctance of some patients to make long and costly trips away from their home communities in order to access colorectal cancer screening services. Because of these geographic and health system barriers, there is a critical need to expand colorectal cancer screening options for Alaska Native people. Better tools are needed to overcome the logistical barriers to screening in this population at increased risk of colorectal cancer.

Effective screening tests which are simple, convenient, relatively inexpensive, and minimally invasive would be especially helpful to increase colorectal cancer screening rates and prioritize endoscopy for higher risk and symptomatic patients. However, because the colorectal cancer incidence and mortality rates are so high among Alaska Native people, it is important to carefully choose tests that have greater effectiveness in this population.

A first step in that direction is the Alaska Native Tribal Health Consortium's *Evaluation of the Fecal Immunochemical Test for Colorectal Cancer Screening in the Alaska Native Population Study* (2008-2012), which enrolled 300 participants in a study comparing guaiac-based fecal occult blood test (gFOBT) with the newer fecal immunochemical fecal occult blood test (iFOBT) in patients receiving screening and surveillance colonoscopies to assess the accuracy (sensitivity and specificity) of gFOBT and iFOBT for detection of screen-relevant neoplasia (colorectal cancer and advanced precancer) in Alaska Native people. Previously there has been widespread reluctance to use gFOBT for colorectal cancer screening in Alaska Native people due to a concern that the high prevalence of *H. pylori* infection and other factors lead to excessive false positive tests and poor specificity.

Preliminary results from the study show that the iFOBT had a significantly higher specificity than gFOBT, especially in patients with current *H. pylori* infection. Sensitivity between the two tests was comparable. The false positive rate was significantly higher for gFOBT compared with iFOBT, especially in patients with current *H. pylori* infection. Among participants who were able to adhere to gFOBT-required dietary and medication restrictions, specificity of gFOBT increased but was still significantly lower than iFOBT. The study data suggest that iFOBT offers advantages that may help increase colorectal cancer screening rates in Alaska Native people, and allows for prioritization of colonoscopy for diagnostic and surveillance examinations. However, iFOBT is primarily a test that detects cancer, not precancerous lesions, and so is not as effective as

colonoscopy in preventing cancer in this increased-risk population. However, for patients who refuse colonoscopy or do not want to travel for an initial screening test it represents a potential strategy for expanding colorectal cancer screening. A manuscript is in preparation detailing the results of the study (Redwood D, Provost E, Asay E, Roberts D, Haverkamp D, Perdue D, Bruce M, Sacco F, Espey D. Comparison of guaiac-based and immunochemical fecal occult blood tests for colorectal cancer screening in an Alaska Native population with high prevalence of *Helicobacter pylori* infection. *Prevent Chronic Dis* (in review) 2013).

A follow-up pilot study is planned to start in 2014 to evaluate the feasibility and acceptability of iFOBT in at least two rural/remote regions of Alaska, especially among persons who have previously refused screening by endoscopy. This pilot study aims to lay the groundwork for broader implementation of the use of iFOBT throughout the Alaska Tribal Health System. Objectives will include developing and implementing healthcare system policy changes in those regions in order expand colorectal cancer screening options available to Alaska Native people.

A second cross-sectional stool test study at ANTHC began in 2012: “Stool DNA Screening for Detection of Colorectal Neoplasia in Alaska Native People: An Initial Appraisal (2012-2015).” The objective of this study is to examine next generation stool DNA (sDNA) testing (sensitivity, specificity) in comparison with iFOBT in patients receiving screening or surveillance colonoscopies. Early studies have shown that the stool DNA test detects both colorectal cancer and polyps that lead to cancer, including right-sided colorectal cancers in the colon, more accurately than stool blood tests, but it has not been evaluated in Alaska Native people. Over 600 participants are expected to join the study over the next three years. If the stool DNA test proves more effective than other types of stool tests, then it has the potential for markedly increasing access to colorectal cancer screening among Alaska Native populations living in remote locations, particularly among those unwilling or unable to get colorectal cancer screening by

colonoscopy. Increasing the availability and types of tests for colorectal cancer screening may increase uptake of screening and decrease colorectal cancer incidence and mortality.

Facilitators and Barriers to Screening

The second area of research inquiry is exploring the facilitators and barriers to screening among Alaska Native people. This information can be used to design interventions that target barriers to increase patient willingness to get screening tests completed. Discussions with Community Health Aides who provide the primary care for patients in their communities at the 2008 Annual Community Health Aide Forum identified common barriers to colorectal cancer screening, including discomfort, financial issues (travel costs), lack of knowledge/information about the importance of screening, and logistic issues (time away from family, need for escort for screening colonoscopies due to sedation). A follow up discussion at the 2011 Annual Community Health Aide Forum identified facilitators to getting community members screened: increasing use of health education materials, professional speakers, knowing the current screening rates by community, making improvements in scheduling referrals, appointments, and patient travel, as well as bundling colorectal cancer screening with other wellness appointments. Community Health Aides who completed follow up interviews reported more comfort in promoting cancer screening among their patients once they had gotten cancer education themselves.[246]

Social ecological theory emphasizes influential behaviors, roles and environmental conditions that act as high-impact “leverage points” for enhancing people’s well-being.[222] To this end more research is needed on the use and effectiveness of patient navigators. A pilot project in 2009 by the Alaska Native Tribal Health Consortium in collaboration with a regional tribal health organization involved the creation of a colorectal cancer screening patient navigator position to test the benefits of patient navigation for increasing colorectal cancer screening. Although the project was successful at outreaching to patients to encourage them to get screened, fewer patients completed screening than was

hoped. Healthcare system barriers were identified as a major impediment to screening completion.[72] More research is needed to identify how patient navigators can be integrated into existing Alaska Tribal Health systems of care to enhance the success of colorectal cancer screening efforts.

Likewise, more research is needed on the use of community-level interventions for promoting colorectal cancer screening in the Alaskan setting. One such study was completed in 2013 by the ANTHC Epidemiology Center on the use of a giant inflatable interactive colon exhibit as an educational tool for increasing community members' knowledge, intention, and social support for colorectal cancer screening and prevention. Alaskan adults (n=880) attending community events statewide between March, 2011-March, 2012 completed a short questionnaire before and after walking through a giant colon model (see Figure 1-15 below). The model depicted colorectal cancer stages from normal tissue to advanced adenocarcinoma and included display signs with colorectal cancer prevention tips. Adult community members significantly improved their colorectal cancer knowledge, intention to get screened, and comfort with talking to friends and family about colorectal cancer screening. Furthermore, the giant colon appeared to be equally effective for men and women, those over and under age 50, and Alaska Native and non-Native community members in all three construct domains surveyed (knowledge, intention and social support).[219]

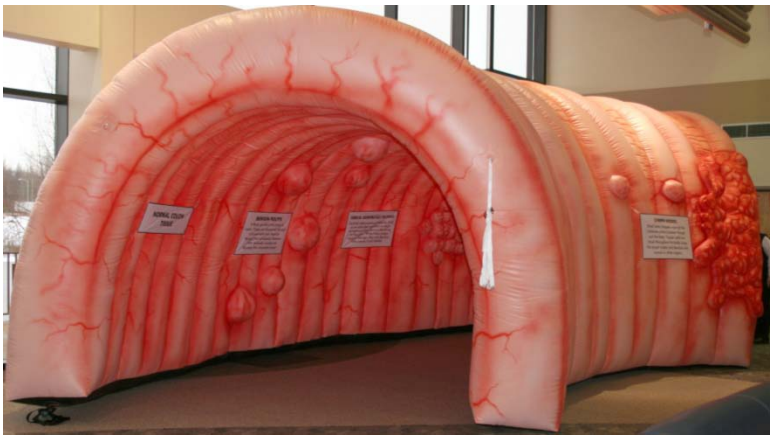


Figure 1-15. 'Nolan' the giant colon.

Lastly, there needs to be more research into how to evaluate the effectiveness of screening interventions, including economic analysis, and measuring the scope of effectiveness and sustainability of intervention outcomes over time. The expansion of colorectal cancer screening test methods, understanding more about effective and sustainable ways to encourage patients to get colorectal cancer screening, and decreasing systems-level barriers all will contribute to promoting colorectal cancer screening among Alaska Native people. These efforts will increase colorectal cancer screening prevalence and, ultimately, decrease the excess morbidity and mortality caused by colorectal cancer among the Alaska Native population.

Literature Cited

1. Levine JS, Ahnen DJ. Clinical practice. Adenomatous polyps of the colon. N Engl J Med. 2006 Dec 14;355(24):2551-7.

2. Edwards BK, Ward E, Kohler BA, Eheman C, Zauber AG, Anderson RN, et al. Annual report to the nation on the status of cancer, 1975-2006, featuring colorectal cancer trends and impact of interventions (risk factors, screening, and treatment) to reduce future rates. Cancer. 2010 Feb 1;116(3):544-73.

3. Winawer SJ, Zauber AG, Ho MN, O'Brien MJ, Gottlieb LS, Sternberg SS, et al. Prevention of colorectal cancer by colonoscopic polypectomy. The National Polyp Study Workgroup. N Engl J Med. 1993 Dec 30;329(27):1977-81.

4. American Cancer Society. Colorectal Cancer Facts & Figures 2011-2013. Atlanta: American Cancer Society; 2011.

5. Stewart SL, Wike JM, Kato I, Lewis DR, Michaud F. A population-based study of colorectal cancer histology in the United States, 1998-2001. Cancer. 2006 Sep 1;107(5 Suppl):1128-41.

6. Fritz A, Percy C, Jack A, et al. International classification of diseases for oncology. 3rd ed. Geneva: World Health Organization; 2000.

7. Siegel R, Naishadham D, Jemal A. Cancer statistics, 2013. CA Cancer J Clin. 2013 Jan;63(1):11-30.

8. U.S. Cancer Statistics Working Group. Atlanta (GA): Department of Health and Human Services, Centers for Disease Control and Prevention, and National Cancer Institute2013.

9. Centers for Disease Control and Prevention. Vital signs: colorectal cancer screening among adults aged 50-75 years - United States, 2008. MMWR Morb Mortal Wkly Rep. 2010 Jul 9;59(26):808-12.

10. Kelly JJ, Schade TL, Starkey BM, White S, Ashokkumar R, Lanier AP. Cancer in Alaska Native people: Forty year report 1969 – 2008. Anchorage, AK: Alaska Native Tumor Registry, Alaska Native Epidemiology Center, Alaska Native Tribal Health Consortium 2012.

11. SEER*Stat Database: Incidence - SEER 13 Regs Research Data, Nov 2010 Sub (1992-2008) <Katrina/Rita Population Adjustment> - Linked To County Attributes - Total U.S., 1969-2009 Counties [database on the Internet]. National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch. 2011 [cited 5/12/2011]. Available from: www.seer.cancer.gov.

12. Surveillance, Epidemiology, and End Results (SEER)*Stat Database: Mortality - All COD, Aggregated With State, Total U.S. (1990-2008) <Katrina/Rita Population Adjustment> [database on the Internet]. National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch. 2011. Available from: www.seer.cancer.gov.

13. SEER*Stat Database: Mortality - All COD, Aggregated With State, Total U.S. (1990-2007) <Katrina/Rita Population Adjustment> [database on the Internet]. National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch. 2011 [cited 5/12/2011]. Available from: www.seer.cancer.gov.

14. Kelly J, Alberts S, Sacco F, Lanier AP. Colorectal cancer in Alaska Native people, 2005-2009. Gastrointest Cancer Res. 2012 Sep;5(5):149-54.

15. Espey DK, Wu XC, Swan J, Wiggins C, Jim MA, Ward E, et al. Annual report to the nation on the status of cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. Cancer. 2007 Nov 15;110(10):2119-52.

16. Perdue D.G., Perkins C., Jackson-Thompson J., Coughlin S.S., Ahmed F., Haverkamp D.S., et al. Regional differences in colorectal cancer incidence, stage, and subsite among American Indians and Alaska Natives, 1999-2004. Cancer. 2008 Sep 1;113(5 Suppl):1179-90.

17. Espey D, Paisano R, Cobb N. Regional patterns and trends in cancer mortality among American Indians and Alaska Natives, 1990-2001. Cancer. 2005 Mar 1;103(5):1045-53.

18. Cooper GS, Chak A, Koroukian S. The polyp detection rate of colonoscopy: a national study of Medicare beneficiaries. The American journal of medicine. 2005 Dec;118(12):1413.

19. Day GE, Provost E, Lanier AP. Alaska Native mortality rates and trends. Public health reports. 2009 Jan-Feb;124(1):54-64.

20. Zauber AG, Lansdorp-Vogelaar I. Changes in risk factors and increases in screening contribute to the decline in colorectal cancer mortality, 1975 to 2000. Gastroenterology. 2010 Aug;139(2):698.

21. Myer PA, Mannalithara A, Singh G, Ladabaum U. Proximal and distal colorectal cancer resection rates in the United States since widespread screening by colonoscopy. Gastroenterology. 2012 Nov;143(5):1227-36.

22. Levin B, Lieberman DA, McFarland B, Smith RA, Brooks D, Andrews KS, et al. Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps, 2008: a joint guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology. CA Cancer J Clin. 2008 May-Jun;58(3):130-60.

23. U.S. Preventive Services Task Force. Screening for colorectal cancer: U.S. Preventive Services Task Force recommendation statement. Ann Intern Med. 2008 Nov 4;149(9):627-37.

24. Levin B, Lieberman DA, McFarland B, Andrews KS, Brooks D, Bond J, et al. Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps, 2008: a joint guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology. Gastroenterology. 2008 May;134(5):1570-95.

25. Elmunzer BJ, Hayward RA, Schoenfeld PS, Saini SD, Deshpande A, Waljee AK. Effect of flexible sigmoidoscopy-based screening on incidence and mortality of colorectal cancer: a systematic review and meta-analysis of randomized controlled trials. PLoS Med. 2012 Dec;9(12):e1001352.

26. Seeff LC, Major A, Townsend JS, Provost E, Redwood D, Espey D, et al. Comprehensive cancer control programs and coalitions: partnering to launch successful colorectal cancer screening initiatives. Cancer Causes Control. 2010 Dec;21(12):2023-31.

27. Vogelaar I, van Ballegooijen M, Schrag D, Boer R, Winawer SJ, Habbema JD, et al. How much can current interventions reduce colorectal cancer mortality in the U.S.? Mortality projections for scenarios of risk-factor modification, screening, and treatment. Cancer. 2006 Oct 1;107(7):1624-33.

28. Seeff, Doroshenk, Berger, Cerulli, DaVanzo. Potential Savings to Medicare from Increased Colorectal Cancer Screening among 50-64 year olds: Report of the National

Colorectal Cancer Roundtable Policy Action Task Group. Washington DCJune 8-10, 2008.

29. Yabroff KR, Mariotto AB, Feuer E, Brown ML. Projections of the costs associated with colorectal cancer care in the United States, 2000-2020. Health economics. 2008 Aug;17(8):947-59.

30. Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010-2020. J Natl Cancer Inst. 2011 Jan 19;103(2):117-28.

31. Zafar SY, Marcello JE, Wheeler JL, Rowe KL, Morse MA, Herndon JE, 2nd, et al. Treatment-related toxicity and supportive care in metastatic colorectal cancer. The journal of supportive oncology. Jan-Feb;8(1):15-20.

32. U.S. Department of Health and Human Services. Healthy People 2020. Washington, DC [12/20/12]; Available from: http://www.healthypeople.gov/2020/.

33. Smith RA, Cokkinides V, Eyre HJ. Cancer screening in the United States, 2007: a review of current guidelines, practices, and prospects. CA Cancer J Clin. 2007 Mar-Apr;57(2):90-104.

34. Cheng TI, Wong JM, Hong CF, Cheng SH, Cheng TJ, Shieh MJ, et al. Colorectal cancer screening in asymptomaic adults: comparison of colonoscopy, sigmoidoscopy and fecal occult blood tests. J Formos Med Assoc. 2002 Oct;101(10):685-90.

35. Greenberg PD, Bertario L, Gnauck R, Kronborg O, Hardcastle JD, Epstein MS, et al. A prospective multicenter evaluation of new fecal occult blood tests in patients undergoing colonoscopy. Am J Gastroenterol. 2000 May;95(5):1331-8.

36. Gopalswamy N, Stelling HP, Markert RJ, Maimon HN, Wahlen SD, Haddy RI. A comparative study of eight fecal occult blood tests and HemoQuant in patients in whom colonoscopy is indicated. Archives of family medicine. 1994 Dec;3(12):1043-8.

37. Hoepffner N, Shastri YM, Hanisch E, Rosch W, Mossner J, Caspary WF, et al. Comparative evaluation of a new bedside faecal occult blood test in a prospective multicentre study. Aliment Pharmacol Ther. 2006 Jan 1;23(1):145-54.

38. Hope RL, Chu G, Hope AH, Newcombe RG, Gillespie PE, Williams SJ. Comparison of three faecal occult blood tests in the detection of colorectal neoplasia. Gut. 1996 Nov;39(5):722-5.

39. Hunt LM, Rooney PS, Bostock K, Robinson MH, Hardcastle JD, Armitage NC. Chemical and immunological testing for faecal occult blood in screening subjects at risk of familial colorectal cancer. Gut. 1997 Jan;40(1):110-2.

40. McMahon BJ, Hennessy TW, Bensler JM, Bruden DL, Parkinson AJ, Morris JM, et al. The relationship among previous antimicrobial use, antimicrobial resistance, and treatment outcomes for Helicobacter pylori infections. Ann Intern Med. 2003 Sep 16;139(6):463-9.

41. Nakama H, Fattah A, Zhang B, Uehara Y, Wang C. A comparative study of immunochemical fecal tests for detection of colorectal adenomatous polyps. Hepatogastroenterology. 2000 Mar-Apr;47(32):386-9.

42. Robinson MH, Kronborg O, Williams CB, Bostock K, Rooney PS, Hunt LM, et al. Faecal occult blood testing and colonoscopy in the surveillance of subjects at high risk of colorectal neoplasia. Br J Surg. 1995 Mar;82(3):318-20.

43. Rozen P, Knaani J, Papo N. Evaluation and comparison of an immunochemical and a guaiac faecal occult blood screening test for colorectal neoplasia. Eur J Cancer Prev. 1995 Dec;4(6):475-81.

44. Woo HY, Mok RS, Park YN, Park DI, Sung IK, Sohn CI, et al. A prospective study of a new immunochemical fecal occult blood test in Korean patients referred for colonoscopy. Clin Biochem. 2005 Apr;38(4):395-9.

45. Li S, Wang H, Hu J, Li N, Liu Y, Wu Z, et al. New immunochemical fecal occult blood test with two-consecutive stool sample testing is a cost-effective approach for colon cancer screening: results of a prospective multicenter study in Chinese patients. Int J Cancer. 2006 Jun 15;118(12):3078-83.

46. Schoenfeld P, Cash B, Flood A, Dobhan R, Eastone J, Coyle W, et al. Colonoscopic screening of average-risk women for colorectal neoplasia. N Engl J Med. 2005 May 19;352(20):2061-8.

47. Young GP, St John DJ, Cole SR, Bielecki BE, Pizzey C, Sinatra MA, et al. Prescreening evaluation of a brush-based faecal immunochemical test for haemoglobin. J Med Screen. 2003;10(3):123-8.

48. Wong BC, Wong WM, Cheung KL, Tong TS, Rozen P, Young GP, et al. A sensitive guaiac faecal occult blood test is less useful than an immunochemical test for

colorectal cancer screening in a Chinese population. Aliment Pharmacol Ther. 2003 Nov 1;18(9):941-6.

49. Smith A, Young GP, Cole SR, Bampton P. Comparison of a brush-sampling fecal immunochemical test for hemoglobin with a sensitive guaiac-based fecal occult blood test in detection of colorectal neoplasia. Cancer. 2006 Nov 1;107(9):2152-9.

50. Lieberman D. Screening for colorectal cancer in average-risk populations. The American journal of medicine. 2006 Sep;119(9):728-35.

51. Levi Z, Hazazi R, Rozen P, Vilkin A, Waked A, Niv Y. A quantitative immunochemical faecal occult blood test is more efficient for detecting significant colorectal neoplasia than a sensitive guaiac test. Aliment Pharmacol Ther. 2006 May 1;23(9):1359-64.

52. Rozen P, Knaani J, Samuel Z. Comparative screening with a sensitive guaiac and specific immunochemical occult blood test in an endoscopic study. Cancer. 2000 Jul 1;89(1):46-52.

53. Ahlquist DA, Sargent DJ, Loprinzi CL, Levin TR, Rex DK, Ahnen DJ, et al. Stool DNA and occult blood testing for screen detection of colorectal neoplasia. Ann Intern Med. 2008 Oct 7;149(7):441-50, W81.

54. Morikawa T, Kato J, Yamaji Y, Wada R, Mitsushima T, Shiratori Y. A comparison of the immunochemical fecal occult blood test and total colonoscopy in the asymptomatic population. Gastroenterology. 2005 Aug;129(2):422-8.

55. U.S. Preventive Services Task Force, Agency for Healthcare Research and Quality. Screening for colorectal cancer: recommendations and rationale. Rockville, MD 2002.

56. Zauber AG, Winawer SJ, O'Brien MJ, Lansdorp-Vogelaar I, van Ballegooijen M, Hankey BF, et al. Colonoscopic Polypectomy and Long-Term Prevention of Colorectal-Cancer Deaths. New England Journal of Medicine. 2012;366(8):687-96.

57. Lieberman D, Nadel M, Smith RA, Atkin W, Duggirala SB, Fletcher R, et al. Standardized colonoscopy reporting and data system: report of the Quality Assurance Task Group of the National Colorectal Cancer Roundtable. Gastrointest Endosc. 2007 May;65(6):757-66.

58. Ashley OS, Nadel M, Ransohoff DF. Achieving quality in flexible sigmoidoscopy screening for colorectal cancer. The American journal of medicine. 2001 Dec 1;111(8):643-53.

59. Rex DK, Petrini JL, Baron TH, Chak A, Cohen J, Deal SE, et al. Quality indicators for colonoscopy. Am J Gastroenterol. 2006 Apr;101(4):873-85.

60. Kisiel JB, Ahlquist DA. Stool DNA screening for colorectal cancer: opportunities to improve value with next generation tests. J Clin Gastroenterol. 2011 Apr;45(4):301-8.

61. Tagore KS, Levin TR, Lawson MJ. The evolution to stool DNA testing for colorectal cancer. Aliment Pharmacol Ther. 2004 Jun 15;19(12):1225-33.

62. Osborn NK, Ahlquist DA. Stool screening for colorectal cancer: molecular approaches. Gastroenterology. 2005 Jan;128(1):192-206.

63. Ahlquist DA, Shuber AP. Stool screening for colorectal cancer: evolution from occult blood to molecular markers. Clinica chimica acta; international journal of clinical chemistry. 2002 Jan;315(1-2):157-68.

64. Parkinson AJ, Gold BD, Bulkow L, Wainwright RB, Swaminathan B, Khanna B, et al. High prevalence of Helicobacter pylori in the Alaska native population and association with low serum ferritin levels in young adults. Clinical and diagnostic laboratory immunology. 2000 Nov;7(6):885-8.

65. Sacco F, Bruce MG, McMahon BJ, Bruden D. A prospective evaluation of 200 upper endoscopies performed in Alaska Native persons. Int J Circumpolar Health. 2007 Apr;66(2):144-52.

66. Zhu J, Davidson M, Leinonen M, Saikku P, Gaydos CA, Canos DA, et al. Prevalence and persistence of antibodies to herpes viruses, Chlamydia pneumoniae and Helicobacter pylori in Alaskan Eskimos: the GOCADAN Study. Clin Microbiol Infect. 2006 Feb;12(2):118-22.

67. Yip R, Limburg PJ, Ahlquist DA, Carpenter HA, O'Neill A, Kruse D, et al. Pervasive occult gastrointestinal bleeding in an Alaska native population with prevalent iron deficiency. Role of Helicobacter pylori gastritis. JAMA. 1997 Apr 9;277(14):1135-9.

68. Kusters JG, van Vliet AH, Kuipers EJ. Pathogenesis of Helicobacter pylori infection. Clin Microbiol Rev. 2006 Jul;19(3):449-90.

69. Johnson JS, Nobmann ED, Asay E, Lanier AP. Dietary intake of Alaska Native people in two regions and implications for health: the Alaska Native Dietary and Subsistence Food Assessment Project. Int J Circumpolar Health. 2009 Apr;68(2):109-22.

70. Ballew C, RossTzilkowski A, Hamrick K, Nobmann E. The Contribution of Subsistence Foods to the Total Diet of Alaska Natives in 13 Rural Communities. Ecology of Food and Nutrition 2006;45(1):1-26.

71. Haverkamp D, Perdue DG, Espey D, Cobb N. A survey of Indian Health Service and tribal health providers' colorectal cancer screening knowledge, perceptions, and practices. J Health Care Poor Underserved. 2011 Feb;22(1):243-57.

72. Redwood D, Provost E, Perdue D, Haverkamp D, Espey D. The last frontier: innovative efforts to reduce colorectal cancer disparities among the remote Alaska Native population. Gastrointest Endosc. 2012 Mar;75(3):474-80.

73. Battelle. Alaska Survey of Endoscopic Capacity (SECAP) Report. Seattle (WA): Prepared for Division of Cancer Prevention and Control, Centers for Disease Control and Prevention 2013. Report No.: Contract No. 200-2008-27956, Task Orders 0002 and 0018. .

74. Redwood D, Joseph DA, Christensen C, Provost E, Peterson VL, Espey D, et al. Development of a flexible sigmoidoscopy training program for rural nurse practitioners and physician assistants to increase colorectal cancer screening among Alaska Native people. J Health Care Poor Underserved. 2009;20(4):1041-8.

75. Winawer SJ, Fletcher RH, Miller L, Godlee F, Stolar MH, Mulrow CD, et al. Colorectal cancer screening: clinical guidelines and rationale. Gastroenterology. 1997 Feb;112(2):594-642.

76. Winawer S, Fletcher R, Rex D, Bond J, Burt R, Ferrucci J, et al. Colorectal cancer screening and surveillance: clinical guidelines and rationale-Update based on new evidence. Gastroenterology. 2003 Feb;124(2):544-60.

77. Lieberman DA, Rex DK, Winawer SJ, Giardiello FM, Johnson DA, Levin TR, et al. Guidelines for colonoscopy surveillance after screening and polypectomy: a consensus update by the US Multi-Society Task Force on Colorectal Cancer. Gastroenterology. 2012 Sep;143(3):844-57.

78. Redwood D, Holman L, Zandman-Zeman S, Hunt T, Besh L, Katinszky W. Collaboration to increase colorectal cancer screening among low-income uninsured patients. Prev Chronic Dis. 2011 May;8(3):A69.

79. Beydoun HA, Beydoun MA. Predictors of colorectal cancer screening behaviors among average-risk older adults in the United States. Cancer Causes Control. 2008 May;19(4):339-59.

80. Christie J, Nassisi D, Wilets I, DuHamel KN, Winkel G, Hilliard R, et al. Assessing endoscopic colorectal screening adherence in an emergency department population. J Natl Med Assoc. 2006 Jul;98(7):1095-101.

81. Anderson JC, Fortinsky RH, Kleppinger A, Merz-Beyus AB, Huntington CG, 3rd, Lagarde S. Predictors of compliance with free endoscopic colorectal cancer screening in uninsured adults. J Gen Intern Med. 2011 Aug;26(8):875-80.

82. Bastani R , Gallardo NV, Maxwell AE. Barriers to Colorectal Cancer Screening Among Ethnically Diverse High- and Average-Risk Individuals. Journal of Psychosocial Oncology. 2001;19(3-4):65-84.

83. Filippi MK, Braiuca S, Cully L, James AS, Choi WS, Greiner KA, et al. American Indian Perceptions of Colorectal Cancer Screening: Viewpoints from Adults Under Age 50. J Cancer Educ. 2012 Oct 20.

84. Jones RM, Vernon SW, Woolf SH. Is discussion of colorectal cancer screening options associated with heightened patient confusion? Cancer Epidemiol Biomarkers Prev. 2010 Nov;19(11):2821-5.

85. Jones RM, Woolf SH, Cunningham TD, Johnson RE, Krist AH, Rothemich SF, et al. The relative importance of patient-reported barriers to colorectal cancer screening. Am J Prev Med. 2010 May;38(5):499-507.

86. Wender RC. Barriers to screening for colorectal cancer. Gastrointest Endosc Clin N Am. 2002 Jan;12(1):145-70.

87. Ward SH, Parameswaran L, Bass SB, Paranjape A, Gordon TF, Ruzek SB. Resident physicians' perceptions of barriers and facilitators to colorectal cancer screening for African Americans. J Natl Med Assoc. 2010 Apr;102(4):303-11.

88. Wolf RL, Zybert P, Brouse CH, Neugut AI, Shea S, Gibson G, et al. Knowledge, beliefs, and barriers relevant to colorectal cancer screening in an urban population: a pilot study. Family & community health. 2001 Oct;24(3):34-47.

89. Wilkins T, Gillies RA, Harbuck S, Garren J, Looney SW, Schade RR. Racial disparities and barriers to colorectal cancer screening in rural areas. J Am Board Fam Med. 2012 May-Jun;25(3):308-17.

90. Coughlin SS, Thompson T. Physician recommendation for colorectal cancer screening by race, ethnicity, and health insurance status among men and women in the United States, 2000. Health Promot Pract. 2005 Oct;6(4):369-78.

91. Klabunde CN, Vernon SW, Nadel MR, Breen N, Seeff LC, Brown ML. Barriers to colorectal cancer screening: a comparison of reports from primary care physicians and average-risk adults. Med Care. 2005 Sep;43(9):939-44.

92. Wee CC, McCarthy EP, Phillips RS. Factors associated with colon cancer screening: the role of patient factors and physician counseling. Prev Med. 2005 Jul;41(1):23-9.

93. Rawl SM, Menon U, Champion VL, May FE, Loehrer P, Sr., Hunter C, et al. Do benefits and barriers differ by stage of adoption for colorectal cancer screening? Health Educ Res. 2005 Apr;20(2):137-48.

94. Quick BW, Hester CM, Young KL, Greiner KA. Self-Reported Barriers to Colorectal Cancer Screening in a Racially Diverse, Low-Income Study Population. J Community Health. 2012 Sep 14.

95. Walsh JM, Kaplan CP, Nguyen B, Gildengorin G, McPhee SJ, Perez-Stable EJ. Barriers to colorectal cancer screening in Latino and Vietnamese Americans. Compared with non-Latino white Americans. J Gen Intern Med. 2004 Feb;19(2):156-66.

96. Tessaro I, Mangone C, Parkar I, Pawar V. Knowledge, barriers, and predictors of colorectal cancer screening in an Appalachian church population. Prev Chronic Dis. 2006 Oct;3(4):A123.

97. Schroy PC, 3rd, Emmons KM, Peters E, Glick JT, Robinson PA, Lydotes MA, et al. Aid-assisted decision making and colorectal cancer screening: a randomized controlled trial. Am J Prev Med. 2012 Dec;43(6):573-83.

98. Jones RM, Devers KJ, Kuzel AJ, Woolf SH. Patient-reported barriers to colorectal cancer screening: a mixed-methods analysis. Am J Prev Med. 2010 May;38(5):508-16.

99. Carcaise-Edinboro P, Bradley CJ. Influence of patient-provider communication on colorectal cancer screening. Med Care. 2008 Jul;46(7):738-45.

100. Marshall DA, Johnson FR, Kulin NA, Ozdemir S, Walsh JM, Marshall JK, et al. How do physician assessments of patient preferences for colorectal cancer screening tests differ from actual preferences? A comparison in Canada and the United States using a stated-choice survey. Health economics. 2009 Dec;18(12):1420-39.

101. Brown ML, Potosky AL, Thompson GB, Kessler LG. The knowledge and use of screening tests for colorectal and prostate cancer: data from the 1987 National Health Interview Survey. Prev Med. 1990 Sep;19(5):562-74.

102. Seeff LC, Nadel MR, Klabunde CN, Thompson T, Shapiro JA, Vernon SW, et al. Patterns and predictors of colorectal cancer test use in the adult U.S. population. Cancer. 2004 May 15;100(10):2093-103.

103. Ling BS, Klein WM, Dang Q. Relationship of communication and information measures to colorectal cancer screening utilization: results from HINTS. J Health Commun. 2006;11 Suppl 1:181-90.

104. Stacy R, Torrence WA, Mitchell CR. Perceptions of knowledge, beliefs, and barriers to colorectal cancer screening. J Cancer Educ. 2008;23(4):238-40.

105. Shapiro JA, Seeff LC, Thompson TD, Nadel MR, Klabunde CN, Vernon SW. Colorectal cancer test use from the 2005 National Health Interview Survey. Cancer Epidemiol Biomarkers Prev. 2008 Jul;17(7):1623-30.

106. Mack LA, Cook LS, Temple WJ, Carlson LE, Hilsden RJ, Paolucci EO. Colorectal cancer screening among first-degree relatives of colorectal cancer patients: benefits and barriers. Ann Surg Oncol. 2009 Aug;16(8):2092-100.

107. Vernon SW, Myers RE, Tilley BC. Development and validation of an instrument to measure factors related to colorectal cancer screening adherence. Cancer Epidemiol Biomarkers Prev. 1997 Oct;6(10):825-32.

108. Paddison JS, Yip MJ. Exploratory study examining barriers to participation in colorectal cancer screening. Aust J Rural Health. 2010 Feb;18(1):11-5.

109. Manne S, Markowitz A, Winawer S, Guillem J, Meropol NJ, Haller D, et al. Understanding intention to undergo colonoscopy among intermediate-risk siblings of colorectal cancer patients: a test of a mediational model. Prev Med. 2003 Jan;36(1):71-84.

110. Stanley SL, King JB, Thomas CC, Richardson LC. Factors associated with never being screened for colorectal cancer. J Community Health. 2013 Feb;38(1):31-9.

111. Manne S, Markowitz A, Winawer S, Meropol NJ, Haller D, Rakowski W, et al. Correlates of colorectal cancer screening compliance and stage of adoption among siblings of individuals with early onset colorectal cancer. Health psychology : official journal of the Division of Health Psychology, American Psychological Association. 2002 Jan;21(1):3-15.

112. Ingrand I, Dujoncquoy S, Migeot V, Ghadi V, Beauchant M, Ingrand P. Interactions among physicians, patients, and first-degree relatives in the familial screening of colorectal cancer in France. Patient Prefer Adherence. 2008;2:47-55.

113. Manne SL, Coups EJ, Winkel G, Markowitz A, Meropol NJ, Lesko SM, et al. Identifying cluster subtypes for intentions to have colorectal cancer screening among non-compliant intermediate-risk siblings of individuals with colorectal cancer. Health Educ Res. 2009 Oct;24(5):897-908.

114. Maxwell AE, Bastani R, Crespi CM, Danao LL, Cayetano RT. Behavioral mediators of colorectal cancer screening in a randomized controlled intervention trial. Prev Med. 2011 Feb 1;52(2):167-73.

115. Breen N, Wagener DK, Brown ML, Davis WW, Ballard-Barbash R. Progress in cancer screening over a decade: results of cancer screening from the 1987, 1992, and 1998 National Health Interview Surveys. J Natl Cancer Inst. 2001 Nov 21;93(22):1704-13.

116. IHS [Indian Health Service] 2012 National GPRA [Government Performance and Results Act of 1993] Clinical Performance Report CCRS, Version 10.0. Indian Health Service 2010 Area Summary Report. Albuquerque, NM: Indian Health Service2012.

117. Meissner HI, Breen N, Klabunde CN, Vernon SW. Patterns of colorectal cancer screening uptake among men and women in the United States. Cancer Epidemiol Biomarkers Prev. 2006 Feb;15(2):389-94.

118. Klabunde CN, Cronin KA, Breen N, Waldron WR, Ambs AH, Nadel MR. Trends in colorectal cancer test use among vulnerable populations in the United States. Cancer Epidemiol Biomarkers Prev. 2011 Aug;20(8):1611-21.

119. Tangka FK, Molinari NA, Chattopadhyay SK, Seeff LC. Market for colorectal cancer screening by endoscopy in the United States. Am J Prev Med. 2005 Jul;29(1):54-60.

120. Ladabaum U, Song K. Projected national impact of colorectal cancer screening on clinical and economic outcomes and health services demand. Gastroenterology. 2005 Oct;129(4):1151-62.

121. Seeff LC, Manninen DL, Dong FB, Chattopadhyay SK, Nadel MR, Tangka FK, et al. Is there endoscopic capacity to provide colorectal cancer screening to the unscreened population in the United States? Gastroenterology. 2004 Dec;127(6):1661-9.

122. Mysliwiec PA, Brown ML, Klabunde CN, Ransohoff DF. Are physicians doing too much colonoscopy? A national survey of colorectal surveillance after polypectomy. Ann Intern Med. 2004 Aug 17;141(4):264-71.

123. Sheffield KM, Han Y, Kuo YF, Riall TS, Goodwin JS. Potentially Inappropriate Screening Colonoscopy in Medicare Patients: Variation by Physician and Geographic Region. JAMA internal medicine. 2013 Mar 11:1-9.

124. Alaska Department of Health and Social Services. Alaska Behavioral Risk Factor Surveillance System. Juneau, AK: Alaska Department of Health and Social Services 2011.

125. IHS [Indian Health Service] 2012 Alaska Area GPRA [Government Performance and Results Act of 1993] Clinical Performance Report CCRS, Version 10.0. Alaska Area 2012 Aggregate Report. Anchorage, Alaska: Alaska Area Native Health ServiceReport run July 30, 2012.

126. Potter MB. Strategies and Resources to Address Colorectal Cancer Screening Rates and Disparities in the United States and Globally. Annu Rev Public Health. 2013 Jan 7.

127. West NJ, Boustiere C, Fischbach W, Parente F, Leicester RJ. Colorectal cancer screening in Europe: differences in approach; similar barriers to overcome. Int J Colorectal Dis. 2009 Jul;24(7):731-40.

128. Sung JJ, Lau JY, Young GP, Sano Y, Chiu HM, Byeon JS, et al. Asia Pacific consensus recommendations for colorectal cancer screening. Gut. 2008 Aug;57(8):1166-76.

129. World Health Organization. Cancer control: Knowledge into action. Early detection. *WHO* guide for effective programmes Geneva: WHO2007.

130. Huxley RR, Ansary-Moghaddam A, Clifton P, Czernichow S, Parr CL, Woodward M. The impact of dietary and lifestyle risk factors on risk of colorectal cancer: a quantitative overview of the epidemiological evidence. Int J Cancer. 2009 Jul 1;125(1):171-80.

131. Ferrari P, Jenab M, Norat T, Moskal A, Slimani N, Olsen A, et al. Lifetime and baseline alcohol intake and risk of colon and rectal cancers in the European prospective investigation into cancer and nutrition (EPIC). Int J Cancer. 2007 Nov 1;121(9):2065-72.

132. Samad AK, Taylor RS, Marshall T, Chapman MA. A meta-analysis of the association of physical activity with reduced risk of colorectal cancer. Colorectal Dis. 2005 May;7(3):204-13.

133. Giovannucci E. An updated review of the epidemiological evidence that cigarette smoking increases risk of colorectal cancer. Cancer Epidemiol Biomarkers Prev. 2001 Jul;10(7):725-31.

134. Slattery ML, Levin TR, Ma K, Goldgar D, Holubkov R, Edwards S. Family history and colorectal cancer: predictors of risk. Cancer Causes Control. 2003 Nov;14(9):879-87.

135. Wu K, Willett WC, Fuchs CS, Colditz GA, Giovannucci EL. Calcium intake and risk of colon cancer in women and men. J Natl Cancer Inst. 2002 Mar 20;94(6):437-46.

136. Kirkegaard H, Johnsen NF, Christensen J, Frederiksen K, Overvad K, Tjonneland A. Association of adherence to lifestyle recommendations and risk of colorectal cancer: a prospective Danish cohort study. BMJ. 2010;341:c5504.

137. Burt RW, Bishop DT, Lynch HT, Rozen P, Winawer SJ. Risk and surveillance of individuals with heritable factors for colorectal cancer. WHO Collaborating Centre for the Prevention of Colorectal Cancer. Bulletin of the World Health Organization. 1990;68(5):655-65.

138. Wark PA, Wu K, van 't Veer P, Fuchs CF, Giovannucci EL. Family history of colorectal cancer: a determinant of advanced adenoma stage or adenoma multiplicity? Int J Cancer. 2009 Jul 15;125(2):413-20.

139. Boardman LA, Lanier AP, French AJ, Schowalter KV, Burgart LJ, Koller KR, et al. Frequency of defective DNA mismatch repair in colorectal cancer among the Alaska Native people. Cancer Epidemiol Biomarkers Prev. 2007 Nov;16(11):2344-50.

140. Umar A, Boland CR, Terdiman JP, Syngal S, de la Chapelle A, Ruschoff J, et al. Revised Bethesda Guidelines for hereditary nonpolyposis colorectal cancer (Lynch syndrome) and microsatellite instability. J Natl Cancer Inst. 2004 Feb 18;96(4):261-8.

141. Le Marchand L, Wilkens LR, Hankin JH, Kolonel LN, Lyu LC. Independent and joint effects of family history and lifestyle on colorectal cancer risk: implications for prevention. Cancer Epidemiol Biomarkers Prev. 1999 Jan;8(1):45-51.

142. Ogino S, Nishihara R, Lochhead P, Imamura Y, Kuchiba A, Morikawa T, et al. Prospective Study of Family History and Colorectal Cancer Risk by Tumor LINE-1 Methylation Level. J Natl Cancer Inst. 2013 Jan 16;105(2):130-40.

143. Lanier AP, Redwood DG, Kelly JJ. The Alaska Education and Research Towards Health (EARTH) Study: Cancer Risk Factors. J Cancer Educ. 2012 Feb 2.

144. Department of Health and Human Services. Health risks in Alaska among Adults: Alaska Behavioral Risk Factor Survey 2009 Annual Report: State of Alaska.

145. Redwood DG, Ferucci ED, Schumacher MC, Johnson JS, Lanier AP, Helzer LJ, et al. Traditional foods and physical activity patterns and associations with cultural factors in a diverse Alaska Native population. Int J Circumpolar Health. 2008 Sep;67(4):335-48.

146. Bersamin A, Zidenberg-Cherr S, Stern JS, Luick BR. Nutrient intakes are associated with adherence to a traditional diet among Yup'ik Eskimos living in remote Alaska Native communities: the CANHR Study. Int J Circumpolar Health. 2007 Feb;66(1):62-70.

147. Murphy NJ, Schraer CD, Theile MC, Boyko EJ, Bulkow LR, Doty BJ, et al. Hypertension in Alaska Natives: association with overweight, glucose intolerance, diet and mechanized activity. Ethnicity & Health. 1997;2(4):267-75.

148. Alaska Native Epidemiology Center. Final Report on the Alaska Traditional Diet Survey. Anchorage, AK: Alaska Native Epidemiology Center, Alaska Native Health Board 2004.

149. Redwood D, Schumacher MC, Lanier AP, Ferucci ED, Asay E, Helzer LJ, et al. Physical activity patterns of American Indian and Alaskan Native people living in Alaska and the Southwestern United States. Am J Health Promot. 2009 Jul-Aug;23(6):388-95.

150. Redwood DG, Lanier AP, Johnston JM, Asay ED, Slattery ML. Chronic disease risk factors among Alaska Native and American Indian people, Alaska, 2004-2006. Prev Chronic Dis. 2010 Jul;7(4):A85.

151. Fuchs, Giovannucci, Colditz, Hunter, Speizer, Willett W. A prospective study of family history and the risk of colorectal cancer. New England Journal Medicine. 1994;331(25):1669-74.

152. Screening for colorectal cancer: U.S. Preventive Services Task Force recommendation statement. Ann Intern Med. 2008 Nov 4;149(9):627-37.

153. Butterworth AS, Higgins JP, Pharoah P. Relative and absolute risk of colorectal cancer for individuals with a family history: a meta-analysis. Eur J Cancer. 2006 Jan;42(2):216-27.

154. Fuchs CS, Giovannucci EL, Colditz GA, Hunter DJ, Speizer FE, WC W. A prospective study of family history and the risk of colorectal cancer. New England Journal Medicine. 1994;331(25):1669-74.

155. St John DJ, McDermott FT, Hopper JL, Debney EA, Johnson WR, Hughes ES. Cancer risk in relatives of patients with common colorectal cancer. Ann Intern Med. 1993 May 15;118(10):785-90.

156. Slattery ML, Kerber RA. Family history of cancer and colon cancer risk: the Utah Population Database. J Natl Cancer Inst. 1994 Nov 2;86(21):1618-26.

157. Winawer SJ, Zauber AG, Gerdes H, O'Brien MJ, Gottlieb LS, Sternberg SS, et al. Risk of colorectal cancer in the families of patients with adenomatous polyps. National Polyp Study Workgroup. N Engl J Med. 1996 Jan 11;334(2):82-7.

158. Pariente A, Milan C, Lafon J, Faivre J. Colonoscopic screening in first-degree relatives of patients with 'sporadic' colorectal cancer: a case-control study. The

Association Nationale des Gastroenterologues des Hopitaux and Registre Bourguignon des Cancers Digestifs (INSERM CRI 9505). Gastroenterology. 1998 Jul;115(1):7-12.

159. Slattery ML, Potter JD, Ma KN, Caan BJ, Leppert M, Samowitz W. Western diet, family history of colorectal cancer, NAT2, GSTM-1 and risk of colon cancer. Cancer Causes Control. 2000 Jan;11(1):1-8.

160. Cho E, Lee JE, Rimm EB, Fuchs CS, Giovannucci EL. Alcohol consumption and the risk of colon cancer by family history of colorectal cancer. Am J Clin Nutr. 2012 Feb;95(2):413-9.

161. Boutron MC, Faivre J, Quipourt V, Senesse P, Michiels C. Family history of colorectal tumours and implications for the adenoma-carcinoma sequence: a case control study. Gut. 1995 Dec;37(6):830-4.

162. Nambiar PR, Gupta RR, Misra V. An "Omics" based survey of human colon cancer. Mutat Res. 2010 Aug 5.

163. Jimenez CR, Knol JC, Meijer GA, Fijneman RJ. Proteomics of colorectal cancer: Overview of discovery studies and identification of commonly identified cancer-associated proteins and candidate CRC serum markers. J Proteomics. 2010 Jun 23;73(10):1873-95.

164. Link A, Balaguer F, Shen Y, Nagasaka T, Lozano JJ, Boland CR, et al. Fecal MicroRNAs as novel biomarkers for colon cancer screening. Cancer Epidemiol Biomarkers Prev. 2010 Jul;19(7):1766-74.

165. Peters U, Hutter CM, Hsu L, Schumacher FR, Conti DV, Carlson CS, et al. Meta-analysis of new genome-wide association studies of colorectal cancer risk. Hum Genet. 2012 Feb;131(2):217-34.

166. National Institute of Health Consensus Development Program, editor. NIH State-of-the-Science Conference. Enhancing use and quality of colorectal cancer screening; 2010; Bethesda, Maryland.

167. Rees G, Martin PR, Macrae FA. Screening participation in individuals with a family history of colorectal cancer: a review. Eur J Cancer Care (Engl). 2008 May;17(3):221-32.

168. Simmang CL, Senatore P, Lowry A, Hicks T, Burnstein M, Dentsman F, et al. Practice parameters for detection of colorectal neoplasms. The Standards Committee, The

American Society of Colon and Rectal Surgeons. Dis Colon Rectum. 1999 Sep;42(9):1123-9.

169. Rex DK, Johnson DA, Lieberman DA, Burt RW, Sonnenberg A. Colorectal cancer prevention 2000: screening recommendations of the American College of Gastroenterology. American College of Gastroenterology. Am J Gastroenterol. 2000 Apr;95(4):868-77.

170. Smith RA, von Eschenbach AC, Wender R, Levin B, Byers T, Rothenberger D, et al. American Cancer Society guidelines for the early detection of cancer: update of early detection guidelines for prostate, colorectal, and endometrial cancers. Also: update 2001--testing for early lung cancer detection. CA Cancer J Clin. 2001 Jan-Feb;51(1):38-75; quiz 7-80.

171. Smith RA, Cokkinides V, Eyre HJ. American Cancer Society guidelines for the early detection of cancer, 2004. CA Cancer J Clin. 2004 Jan-Feb;54(1):41-52.

172. Berg AO, Baird MA, Botkin JR, Driscoll DA, Fishman PA, Guarino PD, et al. National Institutes of Health State-of-the-Science Conference Statement: Family History and Improving Health. Ann Intern Med. 2009 Dec 15;151(12):872-7.

173. Scheuner MT, Wang SJ, Raffel LJ, Larabell SK, Rotter JI. Family history: a comprehensive genetic risk assessment method for the chronic conditions of adulthood. Am J Med Genet. 1997 Aug 22;71(3):315-24.

174. Volk LA, Staroselsky M, Newmark LP, Pham H, Tumolo A, Williams DH, et al. Do physicians take action on high risk family history information provided by patients outside of a clinic visit? Stud Health Technol Inform. 2007;129(Pt 1):13-7.

175. Murff HJ, Greevy RA, Syngal S. The comprehensiveness of family cancer history assessments in primary care. Community genetics. 2007;10(3):174-80.

176. Sweet KM, Bradley TL, Westman JA. Identification and referral of families at high risk for cancer susceptibility. J Clin Oncol. 2002 Jan 15;20(2):528-37.

177. Codori AM, Petersen GM, Miglioretti DL, Boyd P. Health beliefs and endoscopic screening for colorectal cancer: potential for cancer prevention. Prev Med. 2001 Aug;33(2 Pt 1):128-36.

178. Sifri RD, Wender R, Paynter N. Cancer risk assessment from family history: gaps in primary care practice. J Fam Pract. 2002 Oct;51(10):856.

179. Harrison TA, Hindorff LA, Kim H, Wines RC, Bowen DJ, McGrath BB, et al. Family history of diabetes as a potential public health tool. Am J Prev Med. 2003 Feb;24(2):152-9.

180. Zlot AI, Silvey K, Newell N, Coates RJ, Leman R. Family history of colorectal cancer: clinicians' preventive recommendations and patient behavior. Prev Chronic Dis. 2012;9:E21.

181. Schroy PC, 3rd, Barrison AF, Ling BS, Wilson S, Geller AC. Family history and colorectal cancer screening: a survey of physician knowledge and practice patterns. Am J Gastroenterol. 2002 Apr;97(4):1031-6.

182. Murff HJ, Spigel DR, Syngal S. Does this patient have a family history of cancer? An evidence-based analysis of the accuracy of family cancer history. JAMA. 2004 Sep 22;292(12):1480-9.

183. Baier M, Calonge N, Cutter G, McClatchey M, Schoentgen S, Hines S, et al. Validity of self-reported colorectal cancer screening behavior. Cancer Epidemiol Biomarkers Prev. 2000 Feb;9(2):229-32.

184. Qureshi N, Wilson B, Santaguida P, Carroll J, Allanson J, Culebro CR, et al. Collection and use of cancer family history in primary care. Evid Rep Technol Assess (Full Rep). 2007 Oct(159):1-84.

185. Ziogas A, Anton-Culver H. Validation of family history data in cancer family registries. Am J Prev Med. 2003 Feb;24(2):190-8.

186. Glanz K, Grove J, Le Marchand L, Gotay C. Underreporting of family history of colon cancer: correlates and implications. Cancer Epidemiol Biomarkers Prev. 1999 Jul;8(7):635-9.

187. Madlensky L, Esplen MJ, Gallinger S, McLaughlin JR, Goel V. Relatives of colorectal cancer patients: factors associated with screening behavior. Am J Prev Med. 2003 Oct;25(3):187-94.

188. Shvartzman P, Rivkind E, Neville A, Friger M, Sperber AD. Screening intention and practice among first-degree relatives of colorectal cancer patients in southern Israel. Isr Med Assoc J. 2000 Sep;2(9):675-8.

189. Bleiker EM, Menko FH, Taal BG, Kluijt I, Wever LD, Gerritsma MA, et al. Screening behavior of individuals at high risk for colorectal cancer. Gastroenterology. 2005 Feb;128(2):280-7.

190. Richardson JL, Danley K, Mondrus GT, Deapen D, Mack T. Adherence to screening examinations for colorectal cancer after diagnosis in a first-degree relative. Prev Med. 1995 Mar;24(2):166-70.

191. Griffith KA, McGuire DB, Royak-Schaler R, Plowden KO, Steinberger EK. Influence of family history and preventive health behaviors on colorectal cancer screening in African Americans. Cancer. 2008 Jul 15;113(2):276-85.

192. Griffith KA, Passmore SR, Smith D, Wenzel J. African Americans with a family history of colorectal cancer: barriers and facilitators to screening. Oncol Nurs Forum. 2012 May 1;39(3):299-306.

193. Zlot AI, Cox SL, Silvey K, Leman R. The effect of chronic disease family history on healthcare provider practice and patient behavior among Oregonians. Public Health Genomics. 2012;15(3-4):189-200.

194. Armelao F, Orlandi PG, Tasini E, Franceschini G, Franch R, Paternolli C, et al. High uptake of colonoscopy in first-degree relatives of patients with colorectal cancer in a healthcare region: a population-based, prospective study. Endoscopy. 2010 Jan;42(1):15-21.

195. Ruthotto F, Papendorf F, Wegener G, Unger G, Dlugosch B, Korangy F, et al. Participation in screening colonoscopy in first-degree relatives from patients with colorectal cancer. Ann Oncol. 2007 Sep;18(9):1518-22.

196. Bazargan M, Ani C, Bazargan-Hejazi S, Baker RS, Bastani R. Colorectal cancer screening among underserved minority population: discrepancy between physicians' recommended, scheduled, and completed tests. Patient Educ Couns. 2009 Aug;76(2):240-7.

197. Weber MF, Banks E, Ward R, Sitas F. Population characteristics related to colorectal cancer testing in New South Wales, Australia: results from the 45 and Up Study cohort. J Med Screen. 2008;15(3):137-42.

198. Kinney AY, Choi YA, DeVellis B, Kobetz E, Millikan RC, Sandler RS. Interest in genetic testing among first-degree relatives of colorectal cancer patients. Am J Prev Med. 2000 Apr;18(3):249-52.

199. Murff HJ, Peterson NB, Greevy RA, Shrubsole MJ, Zheng W. Early initiation of colorectal cancer screening in individuals with affected first-degree relatives. J Gen Intern Med. 2007 Jan;22(1):121-6.

200. Courtney R, Paul C, Carey M, Sanson-Fisher R, Macrae F, DEste C, et al. A population-based cross-sectional study of colorectal cancer screening practices of first-degree relatives of colorectal cancer patients. BMC Cancer. 2013;13(1):13.

201. Harris MA, Byles JE. A survey of screening compliance among first degree relatives of people with colon cancer in New South Wales. J Med Screen. 1997;4(1):29-34.

202. Bujanda L, Sarasqueta C, Zubiaurre L, Cosme A, Munoz C, Sanchez A, et al. Low adherence to colonoscopy in the screening of first-degree relatives of patients with colorectal cancer. Gut. 2007 Dec;56(12):1714-8.

203. Slattery ML, Murtaugh MA, Lanier AP, Ma KN, Ferucci ED, Etzel RA, et al. Family health history and health behaviors in Alaska Native and American Indian people. J Health Care Poor Underserved. 2009 Aug;20(3):678-94.

204. Schumacher MC, Slattery ML, Lanier AP, Ma KN, Edwards S, Ferucci ED, et al. Prevalence and predictors of cancer screening among American Indian and Alaska Native people: the EARTH study. Cancer Causes Control. 2008 Sep;19(7):725-37.

205. Centers for Disease Control and Prevention National Center for Health Marketing (NCHM) Community Guide Branch. The Guide to Community Preventive Services. Cancer Prevention and Control: Increasing breast, cervical, and colorectal cancer screening [3/5/09]; Available from: http://www.thecommunityguide.org/cancer/index.html.

206. Sarfaty M. How to Increase Colorectal Cancer Screening Rates in Practice: A Primary Care Clinician's Evidence-Based Toolbox and Guide: The American Cancer Society 2008.

207. Sabatino SA, Lawrence B, Elder R, Mercer SL, Wilson KM, DeVinney B, et al. Effectiveness of interventions to increase screening for breast, cervical, and colorectal cancers: nine updated systematic reviews for the guide to community preventive services. Am J Prev Med. 2012 Jul;43(1):97-118.

208. Community Preventive Services Task F. Updated recommendations for client- and provider-oriented interventions to increase breast, cervical, and colorectal cancer screening. Am J Prev Med. 2012 Jul;43(1):92-6.

209. Task Force on Community Preventive Services. Recommendations for client- and provider-directed interventions to increase breast, cervical, and colorectal cancer screening. Am J Prev Med. 2008 Jul;35(1 Suppl):S21-5.

210. Fernald D, Harris A, Deaton EA, Weister V, Pray S, Baumann C, et al. A standardized reporting system for assessment of diverse public health programs. Prev Chronic Dis. 2012;9:E147.

211. Fernandez G, Benlloch M. Interactive exhibits: How visitors respond. Museum International. 2000;52(4):53-9.

212. Heath C, vom Lehn D. Configuring 'interactivity' : Enhancing engagement in science centres and museums. Social Studies of Science. 2008;38(1):63-91.

213. Byrne S, Robles-Rodriguez E. Educational parties as a strategy to promote breast health awareness and screening in underserved female populations. Oncol Nurs Forum. 2009 Mar;36(2):145-8.

214. Englisbe BH, Jimpson GE, Harper GR, Cohen M. Encouraging mammography use among underserved women through a celebration of breast health. Am J Public Health. 1995 Oct;85(10):1446-7.

215. Gellert K, Braun KL, Morris R, Starkey V. The 'Ohana Day Project: a community approach to increasing cancer screening. Prev Chronic Dis. 2006 Jul;3(3):A99.

216. Bean JM, Hutchinson PA. Kids Health Day: one community hospital's approach to health education for families. Patient Educ Couns. 1996 Jan;27(1):53-62.

217. Wu TY, Kao JY, Hsieh HF, Tang YY, Chen J, Lee J, et al. Effective colorectal cancer education for Asian Americans: a Michigan program. J Cancer Educ. 2010 Jun;25(2):146-52.

218. Cueva M, Dignan M, Kuhnley R. Readers' Theatre: A Communication Tool for Colorectal Cancer Screening. J Cancer Educ. 2012 Dec 3.

219. Redwood D, Provost E, Asay E, Ferguson J, Muller J. Giant inflatable colon and community knowledge, intention, and social support for colorectal cancer screening. Prev Chronic Dis. 2013 Mar;10:E40.

220. Klabunde CN, Lanier D, Meissner HI, Breslau ES, Brown ML. Improving colorectal cancer screening through research in primary care settings. Med Care. 2008 Sep;46(9 Suppl 1):S1-4.

221. Agency for Healthcare Research and Quality. Integrated system nearly doubles colorectal cancer screening rate through distribution of inhome kit and followup with nonresponders. Rockville, MD,2010 [2/13/13]; Available from: http://innovations.ahrq.gov/content.aspx?id=2900.

222. Stokols D. Translating social ecological theory into guidelines for community health promotion. Am J Health Promot. 1996 Mar-Apr;10(4):282-98.

223. Joseph DA, DeGroff AS, Hayes NS, Wong FL, Plescia M. The Colorectal Cancer Control Program: partnering to increase population level screening. Gastrointest Endosc. 2011 Mar;73(3):429-34.

224. Sheinfeld Gorin S, Gauthier J, Hay J, Miles A, Wardle J. Cancer screening and aging: research barriers and opportunities. Cancer. 2008 Dec 15;113(12 Suppl):3493-504.

225. Centers for Disease Control and Prevention, Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion. Colorectal Cancer Control Program (CRCCP) Social Ecological Model. February 22, 2011; Available from: http://www.cdc.gov/cancer/crccp/sem.htm.

226. McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. Health Educ Q. 1988 Winter;15(4):351-77.

227. Frieden TR. A framework for public health action: the health impact pyramid. Am J Public Health. 2010 Apr;100(4):590-5.

228. Khankari K, Eder M, Osborn CY, Makoul G, Clayman M, Skripkauskas S, et al. Improving colorectal cancer screening among the medically underserved: a pilot study within a federally qualified health center. J Gen Intern Med. 2007 Oct;22(10):1410-4.

229. Zajac IT, Whibley AH, Cole SR, Byrne D, Guy J, Morcom J, et al. Endorsement by the primary care practitioner consistently improves participation in screening for colorectal cancer: a longitudinal analysis. J Med Screen. 2010;17(1):19-24.

230. Steinwachs D, Allen JD, Barlow WE, Duncan RP, Egede LE, Friedman LS, et al. National Institutes of Health state-of-the-science conference statement: Enhancing use and quality of colorectal cancer screening. Ann Intern Med. 2010 May 18;152(10):663-7.

231. Zapka J. Innovative provider- and health system-directed approaches to improving colorectal cancer screening delivery. Med Care. 2008 Sep;46(9 Suppl 1):S62-7.

232. Myers RE, Hyslop T, Sifri R, Bittner-Fagan H, Katurakes NC, Cocroft J, et al. Tailored navigation in colorectal cancer screening. Med Care. 2008 Sep;46(9 Suppl 1):S123-31.

233. Dignan MB, Burhansstipanov L, Hariton J, Harjo L, Rattler T, Lee R, et al. A comparison of two Native American Navigator formats: face-to-face and telephone. Cancer Control. 2005 Nov;12 Suppl 2:28-33.

234. Jandorf L, Gutierrez Y, Lopez J, Christie J, Itzkowitz SH. Use of a patient navigator to increase colorectal cancer screening in an urban neighborhood health clinic. J Urban Health. 2005 Jun;82(2):216-24.

235. Percac-Lima S, Grant RW, Green AR, Ashburner JM, Gamba G, Oo S, et al. A culturally tailored navigator program for colorectal cancer screening in a community health center: a randomized, controlled trial. J Gen Intern Med. 2009 Feb;24(2):211-7.

236. Petereit DG, Molloy K, Reiner ML, Helbig P, Cina K, Miner R, et al. Establishing a patient navigator program to reduce cancer disparities in the American Indian communities of Western South Dakota: initial observations and results. Cancer Control. 2008 Jul;15(3):254-9.

237. Freeman HP, Rodriguez RL. History and principles of patient navigation. Cancer. 2011 Aug;117(15 Suppl):3539-42.

238. Elkin EB, Shapiro E, Snow JG, Zauber AG, Krauskopf MS. The economic impact of a patient navigator program to increase screening colonoscopy. Cancer. 2012 Dec 1;118(23):5982-8.

239. The Henry J. Kaiser Family Foundation, American Cancer Society, National Colorectal Cancer Roundtable. Coverage of colonscopies under the Affordable Care Act's prevention benefit. 2012; Available from: www.kff.org/healthreform/upload/8351.pdf.

240. Alaska Area Division of Planning, Evaluation and Health Statistics. Alaska area profile: U.S. Department of Health and Human Services Indian Health Service 2007.

241. Haverkamp D. Colorectal Cancer Screening Activities in Indian Country: an Update. Indian Health Service Primary Care Provider. March 2012;37(3).

242. Alaska Tribal Health System Community Health Aide Program. Cancer education for Alaska Native people: The power of digital storytelling. Health Educ Behav. 2010;37:617.

243. Ceuva M, Kuhnley R, Revels L, Lanier A, Dignan M. “It’s Our Voices” Cancer-Related Digital Stories by Alaska’s Community Health Workers. Adult Education Research Conference; Toronto, Ontario Canada2011.

244. Indian Health Service 2007 National Government Performance and Results Act of 1993 Clinical Performance Report CRS. Alaska Area 2007 Aggregate Report. Anchorage, Alaska: Alaska Area Native Health Service2007.

245. Seeff LC, Richards TB, Shapiro JA, Nadel MR, Manninen DL, Given LS, et al. How many endoscopies are performed for colorectal cancer screening? Results from CDC's survey of endoscopic capacity. Gastroenterology. 2004 Dec;127(6):1670-7.

246. Kuhnley R, Cueva M. Learning about cancer has brightened my light: cancer education for Alaska Community Health Aides and Community Health Practitioners (CHA/Ps). J Cancer Educ. 2011 Sep;26(3):522-9.

CHAPTER 2

Executive Summary

Colorectal cancer (CRC) is the second leading cause of cancer mortality and the leading cause of new cases of cancer among Alaska Native people. First-degree relatives (FDRs) of CRC patients have twice the risk as the average population. Therefore, first-degree relatives are an increased risk sub-population within the larger Alaska Native population that experiences a significant health disparity due to CRC. Efforts to increase CRC screening rates have been undertaken by various tribal health organizations throughout the Alaska Tribal Health System (ATHS). Some projects have included training rural mid-level providers in flexible sigmoidoscopy; provision of itinerant endoscopy services at rural tribal health facilities; increasing patient navigator services; and stool test research studies. There have also been some efforts to increase screening specifically by Alaska Native first-degree relatives of CRC patients. However, no program evaluations have been conducted of these activities, nor have any studies previously assessed the extent to which these activities have been occurring throughout the ATHS.

As will be discussed in detail in Chapter 4, program evaluation uses social research methods to investigate the effectiveness of health interventions. Program evaluation includes evaluation design, data collection, data analysis and interpretation, and report dissemination. Program evaluations can be completed at all stages of a program's existence, from pre-implementation, currently implemented, or outcome and impact evaluations of long-standing programs. Findings about program design and implementation provide valuable feedback that can be used to improve program operations.[1]

This study used the Framework for Program Evaluation in Public Health developed by the Centers for Disease Control and Prevention,[2] as a primary structure for developing the

research aims, hypotheses and methodology. Elements of participatory research and evaluation were also used to inform the research structure, including the community-based participatory research (CPBR) model.[3-6] The CBPR approach reflects a profound shift to a more egalitarian balance between program evaluators and communities. Some of the important CBPR principles for program evaluation include an emphasis on building capacity, translating findings into sustainable action, and disseminating results in respectful ways.[7-11] Furthermore, the tribal participatory research and evaluation model was used to increase the cultural relevancy of the program evaluation with the ultimate goal of improving the health care services for Alaska Native people.[12-17]

Research Aims, Hypotheses and Methodology

Research Aim I

The first research aim of this study was to perform a survey of all Alaska Tribal Health System facilities for use of family history for CRC screening. Although a few studies have been done on collection of family history for cancer outreach,[18, 19] no systematic survey has been conducted on the use of family histories for increasing CRC screening among Alaska Native people. Two sub-aims included surveying providers at Alaska tribal health facilities on the types of outreach used for encouraging family members of CRC patients to get screened as well as determining barriers to CRC screening and potential tools to improve CRC screening throughout the Alaska Tribal Health System. The research hypothesis for this aim was that conducting a survey of Alaska Tribal Health System facilities could provide information on current outreach practices and identify areas of need for further training and education.

A study design which incorporated key informant interviews was chosen to provide insight into the programs and screening outreach practices available at the regional level.[20] The study design for the family history outreach key informant interviews was a census of all ATHS tribal health organizations that either provide CRC screening or refer

patients to other facilities for screening. Regional THO representatives who were knowledgeable about CRC outreach at their tribal health facilities were asked to participate in the key informant interviews.[21] An initial email describing the project was sent to ATHS regional contacts requesting that they participate in the interview or identify another individual who would be better able to provide the information requested. If participants did not respond to the initial or follow-up emails, follow-up phone calls were made to elicit response. Interviews were conducted by telephone and recorded on paper data collection sheets prior to entry into an electronic database (SPSS for Windows, Version 16.0 (IBM, Chicago, Illinois). The key informant moderator's guide was developed specifically for this study based on previous ATHS surveys on CRC tracking and surveillance. The survey was reviewed by an outside expert in questionnaire design (Dr. B. Rogers, Tufts University) and pilot tested before the initiation of data collection with members of the priority population. The interview was designed so that the administration time would range from 15-25 minutes to allow enough time to gather the relevant information but not overly burden participants. The interview questionnaire was semi-structured and included a mix of quantitative (yes/no) and qualitative (open-ended) questions to allow participants the opportunity to provide more in-depth responses. Statistical software (SPSS for Windows, Version 16.0 Chicago, Illinois, 2007) was used to analyze quantitative data (counts, frequencies). A manuscript on the study: "Use of Family History for Colorectal Cancer Outreach in the Alaska Tribal Health System," details the survey results of ATHS providers on CRC screening outreach activities and barriers and facilitators, which found that CRC screening outreach was common in the ATHS, but significant barriers still exist, especially for outreach to FDRs, predominately a lack of dedicated staff and resources. This manuscript appears as Chapter 3 of the present work.

Research Aim II

The second research aim of this study was to assess the efforts of the Alaska Native CRC Family Outreach Program by conducting a process evaluation of the program.[2, 20, 22] A

process evaluation design was chosen to explore how the program was developed and implemented, in order to disentangle the factors involved in the success and challenges of the program, and to help identify the key components involved.[1, 23] The essential function of process evaluation is to provide insight into why a program or intervention does or does not work. Some key process evaluation components include the larger social *context* that the program is situated within; the *reach*, or proportion of the intended audience that actually participates in the intervention; the *dose delivered* and *dose received* of the intervention; the program *fidelity*, or how well the program was delivered as planned; *implementation*, which describes the extent to which the intervention was implemented, and *recruitment*, or how the program participants were actually approached and encouraged to join the program. All of these components relate to the eventual success or failure of a given program.[1, 24] In addition to providing descriptive information for analyzing the effects of a given program, process evaluation as a tool offers a way to potentially avoid Type III errors in the evaluation analysis plan.[25] Many public health evaluators are aware of Type I errors (rejecting a "true" null hypothesis (e.g. a false positive), or Type II errors (failing to reject a "false" null hypothesis (e.g. a false negative). Fewer evaluators and researchers take into account Type III errors, which are sometimes referred to as "providing the right answer to the wrong question," or "correctly rejecting the null hypothesis for the wrong reason."[1] Type III errors have important consequences for understanding the benefits of a given intervention or program, including potentially misinterpreting the true effects of that intervention.[26] By examining whether the program was carried out as intended and if not, how it varied from the original plan, the potential for Type III errors can be lessened.[25]

No theoretical framework was used to originally design the Alaska Native CRC Family Outreach Program, nor was a community assessment done prior to program initiation. Over the ten years that the program has been in existence there has not been a program evaluation conducted. The research hypothesis was that a process evaluation of the Alaska Native CRC Family Outreach Program could provide qualitative data for

informing future outreach efforts to this increased-risk population. The goal of the process evaluation was to identify themes within key components of the program. The process evaluation sought to answer the following questions within the key components of the program: What led to the formation and evolution of the program? What were participant outreach responses? What were the successes and strengths of the program, and what were some of the program barriers and challenges?

The evaluation plan used qualitative research methods[27] including key informant interviews with past and present program Alaska Native and non-Native stakeholders. Key informant semi structured interviews formed a central line of evidence in this evaluation to provide in-depth qualitative data. Key informants were selected to ensure that historical and current program staff and managers, as well as key stakeholders involved in the creation of the Alaska Native CRC Family Outreach Program were represented. A snowball sampling technique[28] was used to identify past or present informants who might have relevant information to share. Interviews were conducted until all potential informants had given an interview or declined at which point it was determined that saturation had been reached. The interview guide was developed in consultation with the program director and included 21 semi structured open-ended process evaluation questions. All interviews were conducted in person. The interviews were audio taped and transcribed verbatim. The transcripts were thematically coded using established qualitative methodology and software (QSR International NVivo Version 10, Burlington, MA). Document review was used in conjunction with the key informant interview to fill in dates for when key program changes or decisions occurred as well as providing additional insights into the program development, evolution, strengths, and challenges. Document sources included the CRC screening program coordinator's email archive, hard copies of historic meeting minutes, reports to funders and program progress reports, and other correspondence and program notes. A manuscript on the study: "A Process Evaluation of the Alaska Native Colorectal Cancer Family History Outreach Program," provides the process evaluation results of the Alaska Native CRC Family

Outreach Program (2000-2012) including its formation, evolution, and successes and challenges. A logic model was built of the program, and key themes included an incremental approach which led to a fully formed unique outreach program and the need for dedicated staff to provide culturally competent patient navigation. Challenges identified included differing FDR responses to screening outreach, health system data access and coordination, and the impact of reliance on grant funding for program sustainability. Program participant data, such as surveys of FDRs, were not included in the current study as the focus was on the program development, successes and challenges and opportunities for improvement in outreach efforts. Further research is needed to address participant level barriers to screening, in conjunction with the data compiled as part of this program of study. This manuscript appears as Chapter 4 of the present work.

Research Aim III

The third research aim of this study was to perform an outcome evaluation of the Alaska Native CRC Family Outreach Program to assess whether the program helped increase screening rates among family members of Alaska Native people with CRC. The research hypothesis was that the Alaska Native CRC Family Outreach Program increases the likelihood that first-degree relatives will get screened for CRC. The program database of CRC patients and their FDRs was used to provide the data source for the study. Statistical software (SPSS for Windows, Version 16.0 Chicago, Illinois, 2007) was used to analyze quantitative outcome evaluation data (counts, frequencies, chi-square tests of association, linear regression). All analyses were 2-tailed, and significance was set at $p<0.05$.

A manuscript detailing the results of the study analysis: “Colorectal Cancer Screening Adherence among Alaska Native First-degree Relatives of Colorectal Cancer Patients,” provides the results of the outcome evaluation of the Family History Outreach Program which found despite increasing programmatic outreach and FDR screening rates, a large proportion of Alaska Native FDRs were still due for screening, especially rural-dwelling and older FDRs. This study found that overall, CRC screening and awareness is

increasing among the Alaska Native population, including among FDRs. However, many Alaska Native FDRs remain unscreened. There is a critical need for more research into FDR barriers and facilitators to CRC screening, as well as how the ATHS can more systematically promote screening among this increased-risk population and reduce morbidity and mortality due to this preventable disease. This manuscript appears as Chapter 5 of the present work.

Research Aim IV

The last research aim was to use the results of the ATHS survey and the case study to provide recommendations for Indian Health Service, tribal, or urban Indian facilities on the use of family history to improve outreach for CRC screening for AI/AN populations. The research hypothesis was that the Alaska Native CRC Family Outreach Program can provide a model for other Indian Health Service/Tribal/Urban Indian Health (I/T/U) facilities seeking to improve screening of populations at increased risk for CRC. Findings relevant to this research aim are included in the three manuscripts detailed above. In order to disseminate the research findings a presentation will be made to Alaska tribal health representatives in August, 2013. Once published, the three manuscripts will be widely distributed to representatives working in CRC screening at Alaska tribal health organizations, as well as to the Indian Health Service Task Force on CRC, for discussion and promotion among the IHS Task Force members and member organizations.

Research Review Process

The Alaska Area Institutional Review Board (IRB) (Reference #2011-02-003), the University of Alaska Fairbanks IRB (Reference #234570-1) and the Alaska Native Tribal Health Consortium and Southcentral Foundation research and ethics committees as well as the relevant tribal privacy officers reviewed and approved the study protocol. It was also approved for clearance by the Centers for Disease Control and Prevention Division of Cancer Prevention and Control, which funded the study.

The main role of the Alaska Area Institutional Review Board (IRB) is to protect the interests of research participants in the Alaska Native Health Care System and to ensure that the research projects meet the requirements of federal regulations. All researchers wanting to conduct studies among Alaska Native people must get permission from this board. Furthermore, if the Alaska Area IRB determines a project to be research, then researchers must get permission from the applicable human protections committee of the tribal health organizations in the regions in which they wish to conduct their research. Multiple Tribal review and approvals may need to be obtained prior to initiation of research projects.

Research Timeline

The program evaluation proposal was submitted to the Alaska Area IRB in February, 2011, and a final approval letter of "Exempt Research" was received seven months later. The Tribal review process (which included concept proposal approval) started in June, 2011, and final Tribal approvals were received five months later in November, 2011. The entire process from start to finish took ten months for final approval. It is important to note that at no point in the process was this project seen as anything more than minimal risk by each of the review bodies; nonetheless, the approval process still took a significant amount of time for completion due simply to the steps required in the process and review committee schedules. See Appendix E for a graphic timeline display of the Alaska Area IRB and Tribal review process for the study. Two subsequent study modifications also went through the AAIRB review and approval process but are not detailed here. The PhD dissertation defense presentation and written dissertation also went through the relevant tribal review and clearance processes.

2011

- February 9: Submitted proposal to Alaska Area IRB
- April 19: AAIRB reviewed proposal
- June 2: Received AAIRB modifications required letter
- June 23: Submitted PI response to AAIRB
- June 23: Submitted proposal to ANTHC Research Abstracts Manuscripts Proposals (RAMP) Committee
- June 23: Submitted proposal to SCF tribal concept review
- July 19: AAIRB reviewed PI response letter
- July 27: Concept proposal reviewed and approved by SCF Research Oversight Committee (ROC)
- August 1: Submitted proposal to ANTHC Privacy Officer (as per AAIRB requirements)
- August 1: Submitted proposal to SCF Privacy Officer (as per AAIRB requirements)
- August 3: Submitted proposal to CDC Project Officer for review and approval
- August 9: Concept proposal reviewed and approved by SCF Executive Committee
- August 16: Received concept proposal approval letter from SCF Executive Committee
- August 17: Received AAIRB approval letter (determination of Exempt Research)
- August 24: ANTHC Privacy Officer determined that a Waiver of Authorization required
- August 25: Submitted proposal to SCF Executive Committee for full proposal review
- August 25: Submitted proposal to ANTHC Abstracts Manuscripts Proposals (AMP) Research Review Committee for review
- August 30: Submitted draft Waiver of Authorization to ANTHC Privacy Officer for review
- August 30: Proposal approved by CDC Project Officer
- September 2: Received ANTHC Privacy Officer review and approval

- September 2: ANTHC Privacy Officer determines that Waiver of Authorization NOT required, as AAIRB determined project to be Exempt Research, and if Exempt Research then Waiver of Authorization cannot apply.
- September 2: Received Southcentral Foundation Privacy Officer review and approval
- September 20: Submitted to UAF IRB for review and approval
- September 23: Reviewed and approved by ANTHC Abstracts Manuscripts Proposals (AMP) Research Review Committee
- September 30: Received UAF IRB approval as Exempt Research
- October 4: Reviewed and approved by Southcentral Foundation Executive Committee
- October 17: Received Southcentral Foundation Executive Committee approval letter
- November 9: ANTHC Health Research Review Committee (HRRC) reviewed and approved on behalf of ANTHC Board of Directors
- November 15: Received ANTHC Health Research Review Committee (HRRC) approval letter

CHAPTER 3

Use of family history for colorectal cancer outreach in the Alaska Tribal Health System[1]

Abstract

Background: Colorectal cancer (CRC) is the second leading cause of cancer mortality and the leading cause of new cases of cancer among Alaska Native people. First-degree relatives (FDRs) of CRC patients have twice the risk as the average U.S. population.

Purpose: This study assessed the prevalence of CRC screening outreach to FDRs at Alaska tribal health organizations (THOs), use of family history information, barriers to CRC screening, and potential tools to improve CRC screening throughout the Alaska Tribal Health System (ATHS).

Methods: Key informant interviews were conducted by telephone with regional THOs using a semi-structured moderator's guide from October to December, 2012.

Results: Fourteen THOs (82%) participated, of whom 93% provided some type of CRC screening outreach to patients. More than three-quarters (79%) used brochures/patient educational handouts; 71% used mailed patient reminders or phone patient reminders; and 50% used provider reminders. Other types of outreach included health fairs, Alaska Native-specific CRC prevention videos, radio and TV public service announcements, patient birthday cards, and advertisements in local newspapers and tribal newsletters. Phone patient reminders were considered the most useful for encouraging CRC screening (90%). Only half (50%) said their facility provided outreach to increase FDR screening.

Conclusions: CRC screening outreach is common in the ATHS, but significant barriers still exist, especially for outreach to FDRs, including lack of time and dedicated personnel, as well as opportunistic versus systematic CRC screening and limited medical records functionality. Potential tools included more Alaska Native-specific educational materials and provider training on screening guidelines and age-appropriate referrals.

[1]Redwood D, Provost E, Lopez E, Skewes M, Johnson R, Garcia G, Espey E. Use of family history for colorectal cancer outreach in the Alaska Tribal Health System. Prepared for *American Journal Preventive Medicine* 2013.

Background

Alaska Native people are indigenous persons whose ancestors, prior to European contact, occupied lands that are now part of the state of Alaska. Alaska Native people are a culturally and geographically heterogeneous population with over 230 federally recognized widely dispersed tribes. These tribes represent major cultural groups: in the north are the Inupiaq people, in the interior of the state, the Athabascan people, in the southwest live Yup'ik and Cup'ik people, along the Aleutian Chain are the Aleut and Alutiiq people, and along the southeast panhandle live Tlingit, Haida, and Tsimshian people. Approximately half of the 143,000 Alaska Native people in the state live in rural and remote communities that are off the road system and are accessible only by small aircraft, snow machines, or boats.[29, 30] Traditional Alaska Native values vary throughout the state, but share a common thread of respect for others, caring for the land, sharing with family and community members, and honoring the wisdom of Elders.[31]

Western contact in Alaska began in the mid-1700s with Russian explorers and fur hunters, and continued with the purchase of Alaska by the United States government in 1867. During the past 200 years Alaska Native people experienced significant cultural disruption, including prohibitions on the practice of Native language and cultural traditions, conflicts with Western immigrants, as well as considerable population loss through epidemics and forced relocation.[32] Infectious diseases such as measles and influenza were the primary cause of death among Alaska Native people through the 1950s.[33, 34] In 1954, the Parran Report documented significant health disparities among Alaska Native people compared with other United States populations. This led to the initiation of research studies and health programs focusing on tuberculosis, other infectious diseases, and infant and maternal morbidity and mortality.[33, 35] Since the 1950s, infectious disease rates have declined, and rates of chronic diseases have increased. Chronic diseases are now responsible for five out of the ten leading causes of death among Alaska Native people.[36]

Cancer is the leading cause of death among Alaska Native (AN) people.[36] Colorectal cancer (CRC) is the second leading cause of cancer mortality and the leading cause of new cases of cancer among Alaska Native people.[37] For the period, 2005 to 2009, the CRC incidence rate in Alaska Native people was two times the rate in U.S. Whites (84 vs. 43/100,000), and mortality rates are also about twice that of U.S. Whites.[38, 39] Most CRCs begin as polyps which generally progress slowly into cancers. The average time from progression of a polyp to cancer is 10 to 15 years.[40] This long lead-time presents a window of opportunity for screening and intervention. Screening tests, including colonoscopy, flexible sigmoidoscopy, and fecal occult blood tests, can be used to detect CRC, prevent it through removal of precancerous polyps, or treat it if detected early in the disease progression.[41, 42] It has been estimated that if all precancerous polyps were identified and removed before becoming cancerous, CRC incidence and mortality could be reduced by 76% to 90% and 70% to 90%, respectively.[40, 43] This has profound personal and social consequences for patients and their families, as well as financial implications for healthcare systems.[44, 45]

Alaska Native people are concerned about the increasing burden of cancer which has led to a focus on cancer prevention within tribal health organizations statewide, collectively called the Alaska Tribal Health System (ATHS). The ATHS consists of 143,131 Alaska Native and American Indian people in 229 federally recognized tribes organized into over 30 Tribal Health Organizations (THOs) providing direct patient care. The ATHS provides cradle-to-grave comprehensive care for tribal members, including CRC screening. The ATHS is a hub and spoke network of small village-based clinics, sub-regional clinics, regional hospitals, with one tertiary care hospital located in Anchorage, Alaska. The tribal village clinics are staffed by Community Health Aides/Practitioners (CHA/Ps), who are laypeople trained as first responders for emergencies and provide basic primary and preventive village-based healthcare under supervision of physicians within the ATHS. Sub-regional clinics are generally staffed by CHA/Ps and midlevel providers. Regional hospitals provide inpatient, outpatient, and emergency services and are staffed by

midlevel providers and physicians.[46] In many parts of Alaska the regional THO is the only healthcare provider available for both Native and non-Native residents.

Because of the disproportionate burden of CRC among Alaska Native people, it is important to identify those at highest risk and encourage them to receive appropriate screening.[47] First-degree relatives (FDRs: parents, siblings, children) of patients with CRC are almost twice as likely to experience CRC themselves, especially if their family member was affected before age 45.[48-50] National guidelines recommend that people with a family history of CRC undergo cancer screening beginning at age 40 or 10 years before the youngest diagnosed FDR, whichever is earlier.[42, 51, 52] Although the field of molecular epidemiology and genomics is rapidly expanding the potential for identifying persons at risk of CRC; including the discovery of new genetic biomarkers, whole genome association studies (GWAs), and expression profiling and proteomics;[53-55] family history is still one of the most valuable tools which provides predictive value to identify individual patients at increased risk of CRC.[56]

Improving outreach to persons at increased risk of CRC due to family history is critical to efforts to reduce CRC morbidity and mortality.[57] Healthcare professionals in the United States have long used family history information collected from individuals as a risk assessment tool.[58] However, family histories are rarely used to identify and provide systematic outreach to those at increased risk for disease, especially for CRC,[59] and studies have shown that documentation of family cancer history in medical records is lacking in over half of primary care patients.[60, 61]

Purpose

Although a few studies have been done on collection of family history for cancer outreach,[18, 19] no systematic survey has been conducted on the use of family histories for increasing CRC screening among Alaska Native people. The primary objective of this study was to assess the prevalence of CRC screening outreach based on family history in

the Alaska Tribal Health System (ATHS), as well as how family history information was collected and used for outreach. Lastly, the study elicited responses from regional tribal health providers on barriers to CRC screening and potential tools and activities that could improve family member outreach and screening more systematically throughout the ATHS.

Methods

The study design for the family history outreach key informant interviews was a census of all ATHS tribal health organizations that either provide CRC screening or refer patients to other facilities for screening (n=17). Regional THO representatives who were knowledgeable about CRC outreach at their tribal health facilities were asked to participate in the key informant interviews (October to December 2012). An initial email describing the project was sent to ATHS regional contacts requesting that they participate in the interview or identify another individual who would be better able to provide the information requested. If participants did not respond to the initial or follow-up emails, a follow-up phone call was made to elicit response. Interviews were conducted by telephone and recorded on data collection sheets prior to entry into a database (SPSS for Windows, Version 16.0 (IBM, Chicago, Illinois). The key informant moderator's guide was developed specifically for this study based on previous ATHS surveys, and pilot tested before the initiation of data collection with members of the priority population. Interview administration time ranged from 15-25 minutes. The interview design was semi-structured and included a mix of quantitative (yes/no) and qualitative (open-ended) questions to allow participants the opportunity to provide more in-depth responses.

The interview instrument included questions regarding CRC screening outreach methods used at the THO, such as patient wellness handouts, provider reminders, mailed or telephone patient reminders, or other tools for CRC screening outreach. The interviewer then asked whether the THO provided CRC screening outreach specifically to family members of patients with CRC, what types of outreach were used for those family

members, and whether there was outreach provided specifically to FDRs of CRC patients. The interviewer also queried how family members of CRC patients were identified, such as by histories in the electronic health record, in the patient chart, asking CRC patients directly for lists of their family members, taking family histories when patients came to the tribal health facility, or other methods. For each method, the informant was asked who at the THO collects the family history information, where the information is stored, and how (or if) that information is used for outreach. Any THO which reported not offering CRC screening outreach to patients was queried as to their perceived barriers to providing that service. All respondents were asked what they thought would help their THO expand CRC screening outreach to patients. Lastly, informants provided feedback on what types of CRC screening materials and continuing education they thought would be most helpful for their THO and which staff would be most able to use the information, especially for outreach to patients at increased risk of CRC due to family history. The Alaska Area Institutional Review Board (IRB), the University of Alaska Fairbanks IRB and the Alaska Native Tribal Health Consortium and Southcentral Foundation research and ethics committees reviewed and approved the study protocol. It was also approved for clearance by the Centers for Disease Control and Prevention Division of Cancer Prevention and Control, which funded the study.

Results

Fourteen THOs (82%) provided interview data (see Figure 3-1). Two regions elected to provide a written response to the interview instead of by telephone. The regional THOs interviewed serve an estimated 139,118 Alaska Native people, representing 97% of the total Alaska Native population living in Alaska (Data source: IHS 2012 Draft Active User Population Report). At least one staff member was interviewed; however, two THOs had two staff members participate in the interview. Of the 16 people that participated in the key informant interviews; 44% (7) were medical or clinic directors or case managers, 25% (4) were patient navigators, 19% (3) were program coordinators, and 13% (2) were health education staff. Of the THOs surveyed, 8 (57%) provide CRC

screening at their regional tribal health facility, while the remaining THOs refer patients for CRC screening to the Alaska Native Medical Center in Anchorage, Alaska.

Figure 3-1. Map of Alaska Tribal Health System tribal health organizations surveyed, 2012 (dark shaded areas indicate colorectal cancer outreach interview areas completed).

Of the THOs surveyed, 13 (93%) provided at least some CRC screening outreach to patients. A total of 11 (79%) used brochures and patient educational handouts, 10 (71%) used mailed patient reminders, 10 (71%) used phone patient reminders, and 7 (50%) used provider reminders. Of all the outreach tools used, phone patient reminders were considered the most useful for encouraging CRC screening (90%), followed by provider reminders (86%), mailed patient reminders (80%) and brochures (64%). However, respondents felt that these collective methods were not used much by providers at their facilities, and none of the methods were considered sufficient on their own to encourage screening, but rather a variety of methods was better to reach the intended audience.

Respondents were asked to describe other types of CRC screening outreach used by their facility. All but one THO said that they did other types of outreach, including provision of CRC screening information at health fairs and community events, displaying 'Nolan the Giant Inflatable Colon',[62] Alaska Native specific CRC prevention videos, public service announcements on radio and TV, patient birthday cards, medical staff in-services, and advertisements in local newspapers and tribal newsletters. Additionally, many THOs use Centers for Disease Control and Prevention supported CRC Control Program.[63] patient giveaway items, including calendars, water bottles, veggie bags, tee-shirts, berry buckets, and coffee sleeves with CRC prevention messages to help spread the word about screening.

Although general CRC screening outreach is conducted to varying degrees through the ATHS, only half (50%) of the respondents said that they do any sort of outreach explicitly focused on encouraging family members of CRC patients to get screened. A total of 4 (29%) said that they ask CRC patients for a list of their FDRs to provide outreach to them. At 9 (64%) THOs, medical providers take family history if a patient comes in for a health concern. Family history information is entered into the electronic medical record at 7 (50%) THOs. Other types of outreach based on family history varied, including using a database or log to keep track of FDRs in need of screening, sending a specially designed letter outreach letter to FDRs due for screening, distributing family tree worksheets to patients, and provider review of medical records for FDRs to determine their need for screening referral at an earlier age than average-risk patients.

Respondents described many barriers and challenges to increasing CRC screening outreach at their facility to patients at average risk, and even more so for FDRs. The most commonly cited issue was lack of time and dedicated personnel. Respondents said that their tribal health facility generally provides care to patients who come in for a specific medical complaint and then a screening referral might be offered if the provider thinks it is appropriate. For most facilities CRC screening outreach is not part of usual clinical

duties, and if performed is carried out by just one or two individuals, who generally have other additional job responsibilities. Some respondents also pointed to the challenge that most Alaska Native people live in communities where CRC screening is not locally available. Patients therefore have to travel far distances, which involve airplane flights, out of town stays, and weather-related travel delays. This travel is generally costly, time-consuming and makes patients reluctant to complete the screening procedure. Some respondents also gave examples of systemic barriers to increasing outreach, including only having paper medical charts or electronic medical records that lack functionality to create a list of patients who are due for screening or who have a family history of CRC. Lastly, respondents said that patients are oftentimes unaware of the benefits and importance of screening, and that it is difficult to convince some patients to complete CRC screening, especially those who are healthy or asymptomatic or who do not access the medical system very often.

Respondents were also asked what would help them increase screening outreach among the population they serve. Responses varied, from wanting information on how traditional wild foods might assist with cancer prevention, to more Alaska Native-specific materials, to needing templates for outreach letters, telephone scripts, and provider notations in the medical records. One item needed that was mentioned by all respondents was more training for ATHS healthcare providers on CRC screening guidelines and age-appropriate referrals. Respondents reiterated that the most beneficial way to increase screening would be dedicated staff time to talk with patients, attend community events and work with multiple departments within each THO to encourage CRC screening among their specific patient populations (diabetes, tobacco control, etc.). However, respondents did not feel that this had to be a doctor per se, but other types of mid-level or allied healthcare professionals (patient navigators, case managers, etc.) could also effectively provide these types of outreach.

Conclusion

Due to the high incidence and mortality among Alaska Native people, three Alaska THO grantees were funded in 2009 for a five-year grant supported by the Centers for Disease Control and Prevention (CDC) as part of the National CRC Control Program.[63] The financial support of these grants and other funding mechanisms has led to the creation and staffing of CRC screening patient navigator or equivalent positions in 9 of the 17 main regional THOs. These patient navigators provide screening outreach to patients and help decrease behavioral and structural barriers to screening.[64-69] Although dedicated staff time was rated by all respondents as important for increasing outreach, funding for the screening navigation positions is entirely grant-funded, which has important implications for future sustainability of CRC outreach and prevention efforts.

These activities are even more crucial in light of respondent comments that a great deal of the screening done is opportunistic care, that is, healthcare facilities in the ATHS do not have systems in place to facilitate CRC screening. Only if a patient comes in for another reason and it is somehow recognized that the patient is due, then that patient will be scheduled for screening. Family history information was also opportunistically updated in the medical records if a patient came in for care, but most facilities did not provide outreach to FDRs based on that information. This is in contrast to a organized approach, where a healthcare facility has a system in place to notify providers whether average risk and increased risk patients are due for CRC screening along with a method to notify patients that they are due at the age-appropriate interval.[70] This is known collectively as provider reminder systems, and is listed as one of the five recommended best practices for increasing CRC screening by The Guide to Community Preventive Services.[71, 72]

Alaska, like the rest of the United States, faces challenges in addressing increasing healthcare costs, improving access to medical care, and ensuring and improving quality medical care for patients. Timely access to essential medical information by providers at

the point of care is critical to good outcomes for patients and to improving quality and coordination of patient care. Computerized health records have a long history in the ATHS. Each THO maintains health records for users of their system. The majority of these health record systems are electronic, which has the potential for increasing provider ability to note family history in the medical record and use it for outreach to family members. Previously, the main medical record used by all Alaska THOs was the Resource and Patient Management System (RPMS). However, many regional THOs have now moved to using other electronic health records systems, which do not interface with one another and which are not consistent in where family history and previous cancer screening information is placed within the electronic medical record. Some respondents reported trying to set up provider reminders in their electronic medical records system, but lack of staff time to enter accurate data into the system, as well as inconsistency in where information was located in the medical record, has led to widespread inability to use family history and previous cancer screening information for systematic outreach to patients due for screening within the ATHS.

Furthermore, provider reminder is one of the strongest predictors of CRC screening completion among patients.[73-75] Respondents noted that it would be helpful to expand training opportunities for ATHS healthcare providers at all levels of care. This would address knowledge gaps on CRC screening guidelines and age-appropriate referrals,[76] especially for FDRs and other increased risk groups, to help improve screening rates among the Alaska Native population.

Limitations of this study include a study design in which only one or two respondents per regional THO completed the key informant interview. This individual potentially might not have been the best person to answer interview questions on the behalf of the THO. However, potential respondents were selected on the basis of prior knowledge of their THO responsibilities, including CRC screening management. Also, respondents were asked at the beginning of each interview if they felt they were the best person to answer

the questions, and to provide another individual's name if they felt another would be a better candidate for the interview. Only one respondent gave another name, but it was solely to provide additional information on sub-regional outreach efforts. Another potential study limitation is that these results might be subject to social desirability response bias in that respondents may have said that their organization was doing more to promote CRC screening than they actually were. ATHS CRC screening rates might be used to further assess the veracity of self-reported screening outreach efforts. Lastly, although a census sampling design was used to identify organizations for participation, the final sample size was still small, and limits the generalizability of the findings.

This study was conducted to better understand how CRC outreach occurs across the ATHS, and whether family history information is being collected and used for outreach to FDRs of CRC patients. Although reported CRC screening outreach was common in the ATHS, significant barriers to increasing screening were noted; predominately lack of dedicated staff. These study findings may provide insight for Indian Health Service, tribal, or urban Indian facilities seeking to increase screening, especially among family members of CRC patients, and may also have relevance to improving CRC screening for increased risk patients in other healthcare delivery systems nationwide.

Acknowledgements

Funding for this study was provided by the Centers for Disease Control and Prevention Division of Cancer Prevention and Control. We acknowledge the contributions and support of the Indian Health Service and the Alaska Native Tribal Health Consortium Board of Directors. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Literature Cited

1. Steckler A, Linnan L, . Process evaluation for public health interventions and research. San Francisco, CA: Josey-Bass; 2002.

2. Framework for program evaluation in public health. MMWR. 1999 Sep 17;48(RR-11):1-40.

3. Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. Annu Rev Public Health. 2008;29:325-50.

4. Boyer BB, Mohatt GV, Lardon C, Plaetke R, Luick BR, Hutchison SH, et al. Building a community-based participatory research center to investigate obesity and diabetes in Alaska Natives. Int J Circumpolar Health. 2005 Jun;64(3):281-90.

5. Christopher S, Watts V, Knows His Gun McCormick A, Young S. Building and maintaining trust in a community-based participatory research partnership. Am J Public Health. 2008 Jun 12.

6. Yeary K, Flowers E, Ford G, Burroughs D, Burton J, Woods D, et al. Development of a community-based participatory colorectal cancer screening intervention to address disparities, Arkansas, 2008-2009. Prev Chronic Dis. 2011 Mar;8(2):A47.

7. Israel B.A., Eng E., Schulz A.J., Parker E.A., editors. Methods in community-based participatory research for health. San Francisco, CA: Jossey-Bass; 2005.

8. Minkler M, Wallerstein N, editors. Community-based participatory research for health. San Francisco, CA: Jossey-Bass; 2003.

9. Depoy E.D., Gitlin L.N. Introduction to Research: Understanding and Applying Multiple Strategies. Philadelphia, PA: Mosby; 1994.

10. Israel B.A., Schulz A.J., Parker E.A., Becker A.B., Allen A.J. III, Guzman J.R. Critical issues in developing and following community-based participatory research principles. In: Minkler M W, editor. Community-based Participatory Research for Health. San Francisco: Jossey-Bass; 2003. p. 53-76.

11. Redwood D, Leston J, Asay E, Ferucci E, Etzel R, Lanier AP. Strategies for successful retention of Alaska Native and American Indian study participants. J Prim Prev. 2011 Feb;32(1):43-52.

12. Cochran PA, Marshall CA, Garcia-Downing C, Kendall E, Cook D, McCubbin L, et al. Indigenous ways of knowing: Implications for participatory research and community. Am J Public Health. 2008 Jan;98(1):22-7.

13. Smith LT. Decolonizing methodologies: Research and indigenous peoples. New York: Zed Books; 1999.

14. Burhansstipanov L, Christopher S, Schumacher SA. Lessons learned from community-based participatory research in Indian country. Cancer Control. 2005 Nov;12 Suppl 2:70-6.

15. Holkup PA, Tripp-Reimer T, Salois EM, Weinert C. Community-based participatory research: an approach to intervention research with a Native American community. ANS Adv Nurs Sci. 2004 Jul-Sep;27(3):162-75.

16. Noe TD, Manson SM, Croy C, McGough H, Henderson JA, Buchwald DS. The influence of community-based participatory research principles on the likelihood of participation in health research in American Indian communities. Ethn Dis. 2007 Winter;17(1 Suppl 1):S6-14.

17. Chino M, Debruyn L. Building true capacity: indigenous models for indigenous communities. Am J Public Health. 2006 Apr;96(4):596-9.

18. Mack LA, Cook LS, Temple WJ, Carlson LE, Hilsden RJ, Paolucci EO. Colorectal cancer screening among first-degree relatives of colorectal cancer patients: benefits and barriers. Ann Surg Oncol. 2009 Aug;16(8):2092-100.

19. Qureshi N, Wilson B, Santaguida P, Carroll J, Allanson J, Culebro CR, et al. Collection and use of cancer family history in primary care. Evid Rep Technol Assess (Full Rep). 2007 Oct(159):1-84.

20. Harris MJ. Evaluating public and community health programs. San Francisco, CA: Jossey-Bass; 2010.

21. Caldwell JY, Davis JD, Du Bois B, Echo-Hawk H, Erickson JS, Goins RT, et al. Culturally competent research with American Indians and Alaska Natives: findings and recommendations of the first symposium of the work group on American Indian Research and Program Evaluation Methodology. Am Indian Alsk Native Ment Health Res. 2005;12(1):1-21.

22. Worthen BR, Sanders JR, Fitzpatrick JL. Program evaluation: alternative approaches and practical guidelines 2nd ed. New York, NY: Logman, Inc.; 1996.

23. Dehar M-A, Casswell S, Duignan P. Formative and Process Evaluation of Health Promotion and Disease Prevention Programs. Evaluation Review. 1993 April 1, 1993;17(2):204-20.

24. Windsor RA, Whiteside HP, Jr., Solomon LJ, Prows SL, Donatelle RJ, Cinciripini PM, et al. A process evaluation model for patient education programs for pregnant smokers. Tobacco control. 2000;9 Suppl 3:III29-35.

25. Basch CE, Sliepcevich EM, Gold RS, Duncan DF, Kolbe LJ. Avoiding type III errors in health education program evaluations: a case study. Health Educ Q. 1985 Winter;12(4):315-31.

26. Schwartz S, Carpenter KM. The right answer for the wrong question: consequences of type III error for public health research. Am J Public Health. 1999 Aug;89(8):1175-80.

27. Creswell JW, Plano Clark VL. Designing and conducting mixed methods research. Thousand Oaks, California: Sage Publications, Inc.; 2007.

28. Goodman L. Snowball sampling. Annuals Mathmatical Statistics. 1961;32(1):148-70.

29. Lanier AP. Cancer in Circumpolar Inuit. Background information for Alaska. Acta Oncol. 1996;35(5):523-5.

30. U.S. Census Bureau. Census 2010 American Indian Alaska Native Summary File. 2010; Available from: http://factfinder.census.gov.

31. Alaska Native Knowledge Network. Alaska Native values. Fairbanks: University of Alaska Fairbanks; 2006 [cited 2012 March 8]; Available from: http://ankn.uaf.edu/ANCR/Values/index.html.

32. Young T, Bjerregaard P, editors. Health transitions in arctic populations. Toronto, Canada: University of Toronto Press; 2008.

33. Parran T., Elder M.Q. Alaska's health: a survey report to the United States Department of the Interior. Pittsburgh, PA: Graduate School of Public Health, University of Pittsburgh1954.

34. Section of Epidemiology Division of Public Health. Causes of death in Alaska 1950, 1980-1989. In: Services HaS, editor. Anchorage, Alaska: State of Alaska; 1991.

35. Alaska Department of Health & Social Services. Health Status in Alaska, 2000. Juneau, AK: State of Alaska2001.

36. Day G, Holck P, Provost E. Alaska Native Mortality Update: 2004-2008. Anchorage, AK: Alaska Native Epidemiology Center Alaska Native Tribal Health Consortium2011.

37. Kelly JJ, Schade TL, Starkey BM, White S, Ashokkumar R, Lanier AP. Cancer in Alaska Native people: Forty year report 1969 – 2008. Anchorage, AK: Alaska Native Tumor Registry, Alaska Native Epidemiology Center, Alaska Native Tribal Health Consortium 2012.

38. Kelly J, Alberts S, Sacco F, Lanier AP. Colorectal cancer in Alaska Native people, 2005-2009. Gastrointest Cancer Res. 2012 Sep;5(5):149-54.

39. Centers for Disease Control and Prevention. Vital signs: colorectal cancer screening among adults aged 50-75 years - United States, 2008. MMWR Morb Mortal Wkly Rep. 2010 Jul 9;59(26):808-12.

40. Winawer SJ, Zauber AG, Ho MN, O'Brien MJ, Gottlieb LS, Sternberg SS, et al. Prevention of colorectal cancer by colonoscopic polypectomy. The National Polyp Study Workgroup. N Engl J Med. 1993 Dec 30;329(27):1977-81.

41. Smith RA, Cokkinides V, Eyre HJ. Cancer screening in the United States, 2007: a review of current guidelines, practices, and prospects. CA Cancer J Clin. 2007 Mar-Apr;57(2):90-104.

42. U.S. Preventive Services Task Force, Agency for Healthcare Research and Quality. Screening for colorectal cancer: recommendations and rationale. Rockville, MD 2002.

43. Vogelaar I, van Ballegooijen M, Schrag D, Boer R, Winawer SJ, Habbema JD, et al. How much can current interventions reduce colorectal cancer mortality in the U.S.? Mortality projections for scenarios of risk-factor modification, screening, and treatment. Cancer. 2006 Oct 1;107(7):1624-33.

44. Seeff LC, Doroshenk M, Berger BM, Cerulli MA, JE D. Potential Savings to Medicare from Increased Colorectal Cancer Screening among 50-64 year olds: Report of

the National Colorectal Cancer Roundtable Policy Action Task Group. Washington DCJune 8-10, 2008.

45. Yabroff KR, Mariotto AB, Feuer E, Brown ML. Projections of the costs associated with colorectal cancer care in the United States, 2000-2020. Health economics. 2008 Aug;17(8):947-59.

46. Lanier AP. Cancer in Circumpolar Inuit. Acta Oncologica. 1996;35(5):523-5.

47. Perdue D.G., Perkins C., Jackson-Thompson J., Coughlin S.S., Ahmed F., Haverkamp D.S., et al. Regional differences in colorectal cancer incidence, stage, and subsite among American Indians and Alaska Natives, 1999-2004. Cancer. 2008 Sep 1;113(5 Suppl):1179-90.

48. Fuchs CS, Giovannucci EL, Colditz GA, Hunter DJ, Speizer FE, WC W. A prospective study of family history and the risk of colorectal cancer. New England Journal Medicine. 1994;331(25):1669-74.

49. St John DJ, McDermott FT, Hopper JL, Debney EA, Johnson WR, Hughes ES. Cancer risk in relatives of patients with common colorectal cancer. Ann Intern Med. 1993 May 15;118(10):785-90.

50. Slattery ML, Kerber RA. Family history of cancer and colon cancer risk: the Utah Population Database. J Natl Cancer Inst. 1994 Nov 2;86(21):1618-26.

51. Smith RA, Cokkinides V, Eyre HJ. American Cancer Society guidelines for the early detection of cancer, 2004. CA Cancer J Clin. 2004 Jan-Feb;54(1):41-52.

52. Simmang CL, Senatore P, Lowry A, Hicks T, Burnstein M, Dentsman F, et al. Practice parameters for detection of colorectal neoplasms. The Standards Committee, The American Society of Colon and Rectal Surgeons. Dis Colon Rectum. 1999 Sep;42(9):1123-9.

53. Nambiar PR, Gupta RR, Misra V. An "Omics" based survey of human colon cancer. Mutat Res. 2010 Aug 5.

54. Jimenez CR, Knol JC, Meijer GA, Fijneman RJ. Proteomics of colorectal cancer: Overview of discovery studies and identification of commonly identified cancer-associated proteins and candidate CRC serum markers. J Proteomics. 2010 Jun 23;73(10):1873-95.

55. Link A, Balaguer F, Shen Y, Nagasaka T, Lozano JJ, Boland CR, et al. Fecal MicroRNAs as novel biomarkers for colon cancer screening. Cancer Epidemiol Biomarkers Prev. 2010 Jul;19(7):1766-74.

56. National Institute of Health Consensus Development Program, editor. NIH State-of-the-Science Conference. Enhancing use and quality of colorectal cancer screening; 2010; Bethesda, Maryland.

57. Berg AO, Baird MA, Botkin JR, Driscoll DA, Fishman PA, Guarino PD, et al. National Institutes of Health State-of-the-Science Conference Statement: Family History and Improving Health. Annals of Internal Medicine. 2009;151(12):872-7.

58. Berg AO, Baird MA, Botkin JR, Driscoll DA, Fishman PA, Guarino PD, et al. National Institutes of Health State-of-the-Science Conference Statement: Family History and Improving Health. Ann Intern Med. 2009 Dec 15;151(12):872-7.

59. Scheuner MT, Wang SJ, Raffel LJ, Larabell SK, Rotter JI. Family history: a comprehensive genetic risk assessment method for the chronic conditions of adulthood. Am J Med Genet. 1997 Aug 22;71(3):315-24.

60. Volk LA, Staroselsky M, Newmark LP, Pham H, Tumolo A, Williams DH, et al. Do physicians take action on high risk family history information provided by patients outside of a clinic visit? Stud Health Technol Inform. 2007;129(Pt 1):13-7.

61. Murff HJ, Greevy RA, Syngal S. The comprehensiveness of family cancer history assessments in primary care. Community genetics. 2007;10(3):174-80.

62. Redwood D, Provost E, Asay E, Ferguson J, Muller J. Giant inflatable colon and community knowledge, intention, and social support for colorectal cancer screening. Prev Chronic Dis. 2013 Mar;10:E40.

63. Joseph DA, DeGroff AS, Hayes NS, Wong FL, Plescia M. The Colorectal Cancer Control Program: partnering to increase population level screening. Gastrointest Endosc. 2011 Mar;73(3):429-34.

64. Madlensky L, Esplen MJ, Gallinger S, McLaughlin JR, Goel V. Relatives of colorectal cancer patients: factors associated with screening behavior. Am J Prev Med. 2003 Oct;25(3):187-94.

65. Elkin EB, Shapiro E, Snow JG, Zauber AG, Krauskopf MS. The economic impact of a patient navigator program to increase screening colonoscopy. Cancer. 2012 Dec 1;118(23):5982-8.

66. Freeman HP, Rodriguez RL. History and principles of patient navigation. Cancer. 2011 Aug;117(15 Suppl):3539-42.

67. Lasser KE, Murillo J, Medlin E, Lisboa S, Valley-Shah L, Fletcher RH, et al. A multilevel intervention to promote colorectal cancer screening among community health center patients: results of a pilot study. BMC Fam Pract. 2009;10:37.

68. Redwood D, Provost E, Perdue D, Haverkamp D, Espey D. The last frontier: innovative efforts to reduce colorectal cancer disparities among the remote Alaska Native population. Gastrointest Endosc. 2012 Mar;75(3):474-80.

69. Nash D, Azeez S, Vlahov D, Schori M. Evaluation of an intervention to increase screening colonoscopy in an urban public hospital setting. J Urban Health. 2006 Mar;83(2):231-43.

70. Sarfaty M. How to Increase Colorectal Cancer Screening Rates in Practice: A Primary Care Clinician's Evidence-Based Toolbox and Guide: The American Cancer Society 2008.

71. Sabatino SA, Lawrence B, Elder R, Mercer SL, Wilson KM, DeVinney B, et al. Effectiveness of interventions to increase screening for breast, cervical, and colorectal cancers: nine updated systematic reviews for the guide to community preventive services. Am J Prev Med. 2012 Jul;43(1):97-118.

72. Baron RC, Melillo S, Rimer BK, Coates RJ, Kerner J, Habarta N, et al. Intervention to increase recommendation and delivery of screening for breast, cervical, and colorectal cancers by healthcare providers a systematic review of provider reminders. Am J Prev Med. 2010 Jan;38(1):110-7.

73. Coughlin SS, Thompson T. Physician recommendation for colorectal cancer screening by race, ethnicity, and health insurance status among men and women in the United States, 2000. Health Promot Pract. 2005 Oct;6(4):369-78.

74. Klabunde CN, Vernon SW, Nadel MR, Breen N, Seeff LC, Brown ML. Barriers to colorectal cancer screening: a comparison of reports from primary care physicians and average-risk adults. Med Care. 2005 Sep;43(9):939-44.

75. Wee CC, McCarthy EP, Phillips RS. Factors associated with colon cancer screening: the role of patient factors and physician counseling. Prev Med. 2005 Jul;41(1):23-9.

76. Klabunde CN, Frame PS, Meadow A, Jones E, Nadel M, Vernon SW. A national survey of primary care physicians' colorectal cancer screening recommendations and practices. Prev Med. 2003 Mar;36(3):352-62.

CHAPTER 4

A process evaluation of the Alaska Native Colorectal Cancer Family Outreach Program[1]

Abstract

Objectives: This article presents the results of a process evaluation of the Alaska Native (AN) Colorectal Cancer (CRC) Family Outreach Program, which encourages CRC screening among AN first-degree relatives (FDRs: parents, siblings, children) of CRC patients. AN incidence and mortality rates for CRC are the highest of any ethnic/racial group in the United States. FDRs of CRC patients are at increased risk. CRC can be prevented through screening and early detection.

Methods: The evaluation included key informant interviews (August-November, 2012) with AN and non-AN stakeholders and program document review.

Results: Five key process evaluation components were identified: program formation, evolution, outreach responses, strengths, and barriers and challenges. Key themes included an incremental approach which led to a fully formed program and the need for dedicated culturally competent patient navigation. Challenges identified included differing FDR responses to screening outreach, health system data access and coordination, and the impact of reliance on grant funding for program sustainability.

Conclusions: This program evaluation indicates a need for more research into motivating screening behaviors, electronic medical records systems quality improvement projects, and program sustainability planning to continue the dedicated efforts to promote screening in this increased risk population.

[1]Redwood D, Provost E, Lopez E, Skewes M, Johnson R, Garcia G, Christensen C, Sacco F, Espey E. A process evaluation of the Alaska Native Colorectal Cancer Family Outreach Program. Prepared for *Health Promotion Practice* 2013.

Background

Colorectal cancer prevention and first-degree relatives

Colorectal cancer (CRC) is the second leading cause of cancer mortality and the leading cause of new cases of cancer among Alaska Native people.[1] For the period, 2004-2008, the Alaska Native age-adjusted CRC mortality and incidence rates were nearly twice that of United States (U.S.) Whites.[2, 3] Colorectal cancer can be successfully treated if detected early or even prevented through removal of precancerous (adenomatous) polyps. Nationally recommended screening tests include colonoscopy, flexible sigmoidoscopy and fecal occult blood tests.[4, 5] People with a family history of CRC or adenomatous polyps in one or more first-degree relatives (FDRs: parents, siblings, or children) are almost twice as likely to experience CRC themselves, especially if their family member was affected before age 45.[6-8] Screening strategies targeting FDRs of affected cases could contribute to the prevention or early detection of 15% to 20% of CRCs.[9, 10] Alaska Native FDRs are an increased risk population, within a larger Alaska Native population that experiences a significant health disparity due to CRC. Based on national guidelines,[11, 12] the Alaska Tribal Health System CRC Screening Guidelines (June 2008) recommend that Alaska Native people with a first-degree relative or two or more second-degree relatives receive a colonoscopy every five years beginning at age 40 or 10 years before the youngest diagnosed family member, whichever is earlier.

Program overview

The Alaska Native CRC Family Outreach Program is located at the Alaska Native Tribal Health Consortium (ANTHC) in Anchorage, Alaska. ANTHC was formed in 1997 as a statewide non-profit health services organization owned and operated by Alaska Native people to provide health services to members of the 237 tribes throughout Alaska, primarily through small clinics in each community. ANTHC has a Self-Governance Agreement (the Alaska Tribal Health Compact) with the federal Indian Health Service for management of all statewide health services formerly provided by that agency. ANTHC

co-manages the Alaska Native Medical Center (ANMC) in Anchorage, Alaska along with Southcentral Foundation, which is the regional tribal health organization for Anchorage and surrounding communities.

The goal of the Alaska Native CRC Family Outreach Program is to encourage FDRs of CRC patients to get screened for CRC themselves (see Figure 4-1: Program Logic Model). The program activities include asking to CRC patients seen at ANMC for a contact list of their FDRs. CRC patients either are approached for these lists while still in the hospital for cancer treatment, when coming back for follow-up appointments, or are sent a form with a business reply envelope to fill out at home. Furthermore, CRC cases are ascertained annually from the ANTHC Alaska Native Tumor Registry. The contact information given by the CRC patient is entered into a Microsoft Office Access database. A CRC screening patient navigator uses the information to provide direct outreach to Alaska Native family members encouraging them to get screened for CRC using telephone and mailed reminders, scheduling them into the screening clinic, and guiding them through the cancer screening process. First-degree relative lists are also sent annually to regional Tribal Clinical Directors for use by their facilities in identifying patients at increased risk of CRC.

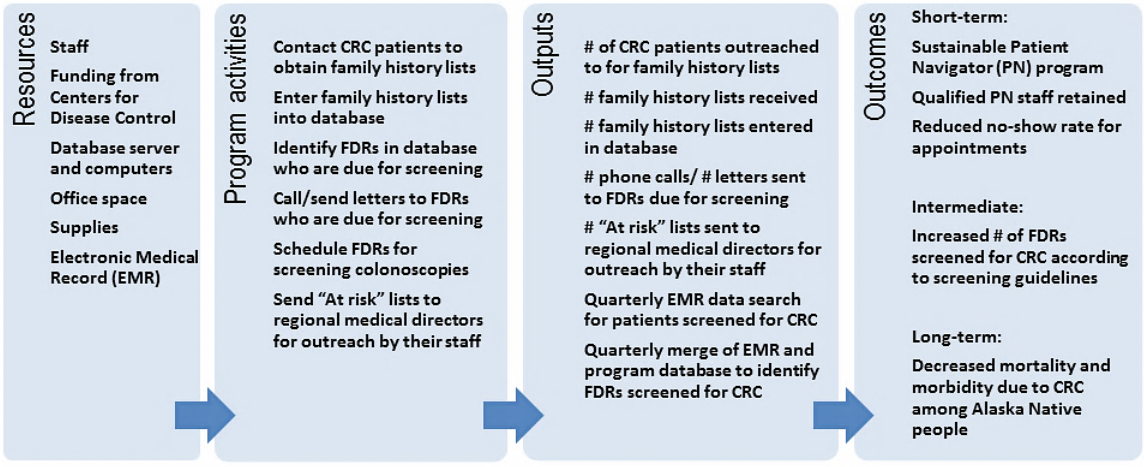


Figure 4-1. Logic model of the Alaska Native Colorectal Cancer Family Outreach Program, 2012.

The program does not currently provide outreach to high risk family members such as those with defined familial syndromes associated with extremely high risks of CRC, such as hereditary non-polyposis colorectal syndrome (HNPCC, or Lynch syndrome) or familial adenomatous polyposis (FAP),[13] which require and receive specialized case management services at ANMC. Likewise, management of surveillance in patients with a personal history of adenomas or CRC is provided by the main CRC screening clinic at ANMC.

Program evaluation

Public health programs have been developed to address some of the significant health disparities experienced by Alaska Native people, such as cancer screening promotion to reduce morbidity and mortality related to breast, cervical and colorectal cancer. Cancer screening program components often include community outreach and education, provider education, direct screening services, and policy and systems changes.[14] Cancer screening provision in Alaska can be challenging due to geographic and health systems access issues.[15-17]

Program evaluation is the "use of social research methods to systematically investigate the effectiveness of social intervention programs […]".[18] Program evaluation can be appreciated as a progression of steps which include designing the evaluation, collecting the data, analyzing and interpreting the data, and reporting the findings (see Figure 4-2: Framework for Program Evaluation in Public Health, Centers for Disease Control and Prevention). Program evaluation can encompass many aspects and occur at many stages of the life of a program; from formative evaluation of programs that are still in the planning phase; to process monitoring and evaluation of currently implemented programs; to outcome and impact evaluation of programs to determine their overall net worth and broader effect.[19] Process evaluation specifically examines how a program was actually implemented, by monitoring program activities and the priority populations

served.[20] Findings about program design and implementation provide valuable feedback that can be used to improve program operations.[21] This study describes the process evaluation of the Alaska Native Colorectal Cancer (CRC) Family Outreach Program, which collects contact information on family members of CRC patients for purposes of outreach and CRC screening. The goal of the process evaluation was to identify themes within key components of the program. The process evaluation sought to answer the following questions: What led to the formation and evolution of the program? What were participant outreach responses? What were the successes and strengths of the program, and what were some of the program barriers and challenges?

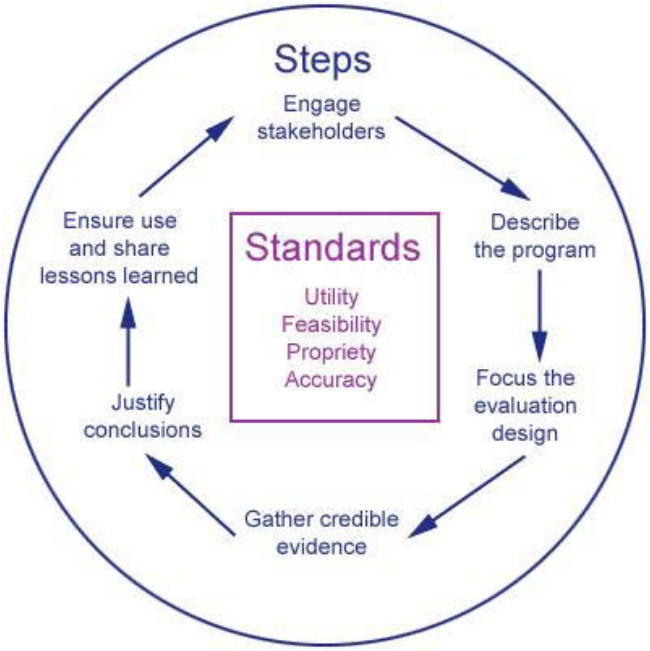


Figure 4-2. Framework for program evaluation in public health, 1999.[22]

Methods

No theoretical framework was used to design the Alaska Native CRC Family Outreach Program, nor was a community assessment done prior to program initiation. Over the ten years that the program has been in existence there has not been a program evaluation conducted. The evaluation plan used qualitative methods[23] including key informant

interviews with past and present program Alaska Native and non-Native stakeholders and program document review, including program progress reports and correspondence. Key informant semi structured interviews formed a central line of evidence in this evaluation. Key informants were selected to ensure that historical and current program staff and managers, as well as key stakeholders involved in the creation of the Alaska Native CRC Family Outreach Program were represented. A snowball sampling technique[24] was used to identify past or present informants who might have relevant information to share. Interviews were conducted until all potential informants had given an interview or declined. The interview guide was developed by the lead evaluator in consultation with the program director and included 21 semi structured open-ended process evaluation questions. All interviews were conducted in person. The interviews were audio taped and transcribed verbatim. The transcripts were coded using established qualitative methodology and software (QSR International NVivo Version 10, Burlington, MA).

The Alaska Area Institutional Review Board (IRB), the University of Alaska Fairbanks IRB and the Alaska Native Tribal Health Consortium and Southcentral Foundation research and ethics committees as well as the relevant tribal privacy officers reviewed and approved the study protocol. It was also approved for clearance by the Centers for Disease Control and Prevention Division of Cancer Prevention and Control, which funded the study.

Results

A total of eight interviews with key informants were conducted between 30 July and 5 September, 2012, including hospital administrators (1), patient navigators (2), program managers (1), data analysts (1), and clinicians (3). All those who declined (n=5) self-reported that it was due to insufficient knowledge of the program. The findings of the key informant interviews were delineated into five key components of the process evaluation. Key components included program formation, evolution, outreach responses, successful

components and strengths of the program, and program barriers and challenges (Table 4-1).

Table 4-1. Key themes of the Alaska Native Colorectal Cancer (CRC) Family Outreach Program process evaluation, 2012.

Key Component	Themes
Program formation	• Incremental approach to program development
Program evolution	• Additional funding used to hire dedicated outreach staff (patient navigators) • Improved outreach tracking system and patient materials • Improved endoscopic access for patients
Outreach responses	• Increased awareness of CRC and the need for screening among population served • Fear of finding cancer • Wanting to prevent cancer by getting screened • Needing help navigating the system to get screened • Familial support for screening
Strengths	• Geographically and ethnically defined patient population • Screening costs covered by Alaska Tribal Health System • Support by hospital leadership (Chief of Surgery) • Only program collecting this information and using it for outreach among Alaska Native people • Dedicated staff time • Alaska Native patient navigators who receive intensive training in motivational interviewing and patient outreach techniques
Barriers and challenges	• Culturally heterogeneous population from across state • Still patients due for screening • Need for more education on benefits of screening (patients) and screening referral guidelines (providers) • Reliance on grant funding for program operations • Need for improved data sharing and reporting in Alaska Tribal Health System

Program formation

The Alaska Native Tumor Registry, which monitors cancer incidence and mortality for all Alaska Native people, has data going back to 1969 that documents a rise in both CRC incidence and mortality among the Alaska Native population which is significantly

higher than the U.S. White population. Those data coupled with the literature showing that FDRs have a higher prevalence of CRC than the average-risk population led to an interest in the late 1990s by the ANMC Chief of Surgery in collecting family information from the Alaska Native CRC patients seen at the hospital. Furthermore, the clinicians who were involved in care of patients with CRC at the time noticed they were seeing more and more patients from the same family, either first- or second-degree relatives, who were also experiencing CRC.

> I think, as a clinician taking care of patients with colorectal cancer, I think it became clear that we were seeing people from the same family. And when we talked to people, the more we talked to them, we found that there were multiple instances where there were people who had first-degree family members or second-degree family members with colon cancer. So I think it started out basically as a clinical impression, and I think that because of that clinical impression and because of the fact that the literature shows higher risks for first-degree relatives that we thought that this was something that we should be pursuing since this is a potentially preventable disease (Hospital Administrator).

The Alaska Native CRC Family Outreach Program began very slowly, first just as a spreadsheet in the late 1990s of 200-300 newly diagnosed Alaska Native CRC patients. In early 2001, a nurse practitioner in the ANMC Surgery Clinic was assigned the task of getting in touch with CRC patients to ask them for contact information for their FDRs. CRC patients were identified either by the surgeons who had diagnosed the CRC or from the weekly hospital Tumor Board. CRC patients were approached either in person if they had not yet left the hospital, or by mailed letter. The hospital's risk management and legal departments reviewed the project and the outreach letter to ensure patient privacy and confidentiality concerns were met. The nurse practitioner was primarily providing screening endoscopy procedures so was not able to dedicate time to outreaching to the identified FDRs. However, a registered nurse was available who sent out some letters to

FDRs. However, no attempt was made to keep track of how many FDRs were getting screened.

At the beginning of the program, much of the relevant family history and screening information was in free text fields in the electronic medical record surgery package which was difficult to navigate and had great variability in where information was put and how it was entered. No funding was available for additional computer programming. There was also a belief at the time that the hospital was going to be changing medical records systems, and so it would not make sense to put more data into the current system. Therefore, a decision was made to collect information outside of the electronic medical record.

Originally kept as a three-ring binder full of FDR contact information, a Microsoft Office Access database was created in 2002 to better manage the collected information. Although beneficial in that the database could be used immediately and contained exactly the variables required, because it was free standing and unconnected to the hospital's medical record systems keeping patient contact and screening information current was difficult and required a lot of staff time that wasn't available in the early years of the program. One key informant stated:

> And then to go through and figure out if the person had actually already had a procedure done; how would we find that out? Where would we find that information? So having it freestanding was a problem but the only way we had right then of keeping track (Clinician).

A further issue was that the data collected were not always complete. Some CRC patients would say they had four children, but they could not remember their birth dates. Others would not know the addresses of their FDRs as they had lost touch over the years, or they gave names that were the same as other names in the medical records system, such that it was not possible to verify the identity of a FDR.

A CRC tracking package within the medical records system was created in 2003 and used briefly to keep track of patients due for screening. This package had the benefit that it could leverage the patient registration and previous screening information from the electronic medical record. It was also able to produce letters to patients, including FDRs, in need of screening. However, all information had to be hand entered, similar to the database; it did not have as many useful fields; it was difficult for staff to navigate; and it was difficult to pull aggregated reports.

> It was difficult at first because it was a free-text environment. So sifting through all the different ways of documentation for colorectal cancer screening and results and other information like family history were there, but the noise surrounding them was significant. The variation in ways of saying the same thing was also significant. And I think that that helped us realize that we needed a better tracking system (Data Analyst).

For these reasons, the CRC tracking package was not used for very long at ANMC, although a version of it is used at one of the regional tribal health organizations to keep track of patients for surveillance colonoscopies.

The Access database is still the primary data management tool used for the program. The database can be used by multiple staff members conducting outreach simultaneously. All patient contact information is kept on a secure research server, and access to the server is password protected. In 2008, a programmer analyst was tasked with increasing the capability of the Access database, most notably by adding fields on FDR screening dates and results, a tracking log to record and display outreach activities and patient notes, and report functions for those activities (number of phone calls made, number of letters sent, appointments kept, etc.). That was the first point at which outcomes of the program could be tracked and evaluated. One program staff member said:

> Well the family history database has undergone--in fact, I don't know if I would recognize it anymore because I know [programmer analyst] made a lot of really good changes to it to make it more user friendly and useful. So I know there are a

> lot of changes that have happened as far as notifications […] keeping track of that is very, very helpful (Clinician).

Program evolution

In April 2007, using funding from the Centers for Disease Control and Prevention, a program assistant was hired to identify FDRs, maintain the FDR database and provide outreach to FDRs to encourage them to get screened, including taking over sending letters from the nurse who had been doing it previously. Along with these FDR project duties the program assistant also performed other duties for the screening colonoscopy clinic, including making appointment reminder and rescheduling calls to patients, maintaining records for surveillance and follow-up, and sending results letters to patients who had completed their screening colonoscopies. The program assistant did not have previous experience in patient outreach and found it difficult initially to know how to motivate FDRs to come in for screening. Additionally, by having multiple job duties, the program assistant was not able to devote as much time to the FDR outreach as had been originally envisioned. Despite this, as shown in Figure 4-3, FDR screening rates increased when the first CRC screening patient navigator was hired from about 25 FDRs screened per year in the early 2000s to 90 screened in 2008. Also, in October 2009, the program assistant's job title was changed to patient navigator to better reflect the job duties associated with the position.

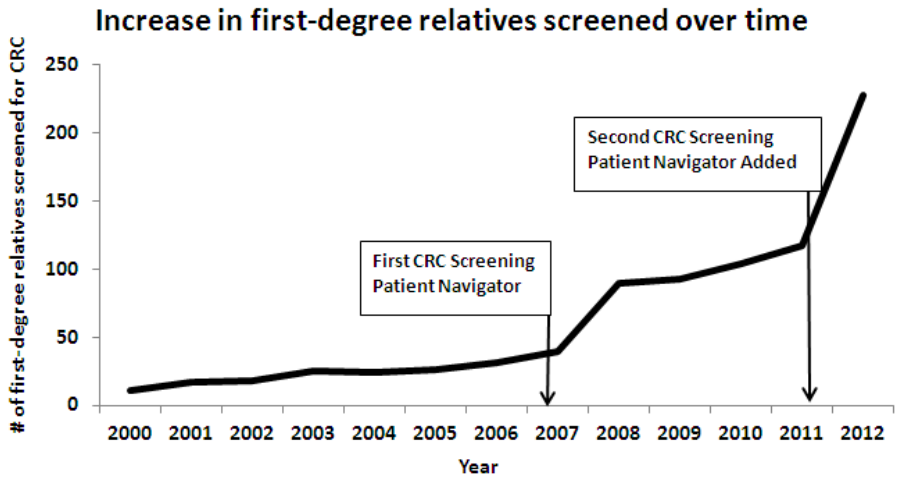


Figure 4-3. First-degree relatives screened from the Alaska Native Colorectal Cancer Family Outreach Program, 2000-2012.

In 2009, the screening endoscopist also started allowing direct referrals, so that low-risk patients did not have to go through a primary care provider in order to schedule a screening colonoscopy. In addition to facilitating direct access, the program also lets providers know that their patients are due for screening due to their FDR increased risk for CRC. The FDR outreach letter was also refined and a picture of the screening endoscopists and patient navigators was added to the letter so that patients would feel more comfortable when the patient navigators contacted them by phone or they came in for screening. A greater emphasis also was placed on sending out lists to regional tribal health organizations of the Alaska Native FDRs living in their areas who were due for screening so that these increased-risk patients could be invited to complete their screening.

In 2012, a second patient navigator was added using research grant funding. The additional staff time almost doubled the number of FDRs screened to 228 from 117 in 2011. At the same time there was also a shift such that CRC screenings no longer occurred in the surgery department, but were moved into a new dedicated space with a screening clinic offering both flexible sigmoidoscopy and colonoscopy services. This

shift brought additional case manager assistants, who were able to take over the clinical duties the patient navigator had been performing previously.

Outreach responses

The original concept for the outreach program was to systematically work from a list of patients at increased risk due to family history in order to help reduce CRC on a population level. The program has found that the most effective way to obtain family history lists from CRC patients is face-to-face interactions. It can be difficult since the cancer patient may be sick, may just had surgery or have just been told they have cancer and need time to deal with their diagnosis and treatment plan. However, in that personal interaction it is possible to sit with the cancer patient and explain that the information collected will be used to help their family members. Sometimes their FDRs are also there helping to take care of the cancer patient, so they can be scheduled for screening at that time.

The patient navigators work to lower barriers to screening, such as helping FDRs find transportation and lodging before the procedure if they are homeless. All key informants reported that dedicated staff time for outreach was the most critical element to increasing screening rates. However, patient beliefs and attitudes also play a role in screening adherence. In general many Alaska Native people are motivated to come in for screening because somebody they know has CRC.

> We would keep records of how many times we've contacted the patients over the years. And then you see someone who calls you up after you've been trying to call them for four years. And you just ask that question, ‘So what made you change your mind?’ And they'll tell you their Uncle George or their best friend at work or somebody had colon cancer (Clinician).

Several key informants pointed out that over the last 15 or 20 years there has been an increased awareness about CRC in the Alaska Native population due to increased education throughout the state and increased availability of screening services. The

Native population as a whole is much more aware of family history as a risk factor, and the need for CRC screening. As more Alaska Native people have gotten screened, the more likely that any given patient who hasn't been screened will be able to talk to somebody who's actually gone through the screening process, who may have had precancerous polyps removed, or who had a cancer found early when it was more easily treated and cured.

For Alaska Native FDRs, there are an additional set of issues that play into screening adherence. FDRs experience conflicting emotions including fear or anger about getting cancer, especially if they are the primary care taker for the cancer patient and see what they are experiencing, particularly if the treatment is unsuccessful and the family member dies from a disease that was diagnosed too late to cure. Sometimes the FDRs do not want to do the procedure and find out that they also have cancer. Sometimes they do not believe that they are at risk themselves. One patient navigator reported:

> I've had people who were just absolutely upset that I called. I told them, “Your family member had colon--.” They're like, “Who?” “Oh, yeah, I guess she did.” And I say, "Well, you are more likely to develop these precancerous polyps.” And they say, "Oh, bunch of baloney! (Patient Navigator)

For other FDRs it is a very strong impetus for them to get screened if they saw a loved one delay seeking care for symptoms.

> Mom just never went in. She was having problems for a long, long time, and she either wouldn't go in, or she just kept putting it off (Clinician).

If they see their family member have the cancer caught early and still be alive and disease free, that can also be a push towards getting screened.

Sometimes the CRC patient will tell their family members that they are at higher risk and encourage them to get screened. Sometimes family relationships can help wherein one FDR will come in for screening to get another FDR in the family to complete their screening, or two siblings will come in for screening at the same time to provide support

and encouragement to one another.

> Often we'll see somebody who has cancer, and when one of the siblings get screened and they kind of push the others to get screened. So I mean I think there's family pressure which works to help, and I think that that makes a difference. I think that the more people that are screened, the more likely any given patient who hasn't been screened will be able to talk to somebody who's actually gone through it (Hospital Administrator).

After screening many FDRs reported feeling a sense of relief, which ends up outweighing the anxiety they experienced before the procedure. FDRs are often relieved to have the program contact them because they know they need to get screened but do not know where to start. Sometimes their primary care doctor does not know they have a family history, which makes it even more important that the program provide outreach encouraging FDRs to get screened.

Even the FDRs who are nonresponsive at first sometimes are more receptive later when they have had time to think about it more or their life circumstances have changed. One clinician noted:

> It’s not that they're not interested or that they will never be interested, it's just that there are different phases in individual humans' willingness to change or be able to actually face change […] They may be going through some kind of crisis, other things going on in their lives, or fishing is going on or berry-picking is going on. But you offer this in November, and they say, ‘Well, when can I get this done? Can I come in? Can I come in tomorrow? Can we do it now?’ I've actually had people say that (Clinician).

Additionally, because the screenings occur within the Alaska Tribal Health System, it gives all Alaska Native FDRs equal access to care, regardless of financial status. By removing the financial burden, it reduces a common barrier to screening experienced by other U.S. populations. However, the colonoscopy preparation and procedures requires

time away from work and/or care of family members, which can be challenging for some patients.

Successful components and strengths of the program

One of the most successful components of the program is the dedication of resources (staff and otherwise) to actively obtaining information on FDRs and then providing outreach to those relatives, especially multiple phone calls, to schedule them for screening. Key informants highlighted that if the program didn't collect the FDR information from CRC patients, then there would be no way of knowing which Alaska Native patients need earlier CRC screening, and at what age they need to be screened.

> I think the main strength of the program is, I don't know of any other program around the country that is actually dedicating resources to going out and finding people that are at risk this way. Most of them are leaving it up to families and people to show up themselves rather than to actually have people dedicated to gathering that information (Program Manager).

For FDRs as well, without the program's efforts many would not know they need to be screened, or how to schedule a screening appointment. And for those who do not follow through with the screening appointments, the program provides outreach to encourage them to reschedule and complete the screening. All of these efforts provide a valuable service to help reduce Alaska Native morbidity and mortality due to this disease.

A further strength is that patient navigators (one male, one female) are Alaska Native themselves, and so have a better perspective on culturally competent ways to motivate patients to obtain screening. One patient navigator commented:

> I think of Native people as a whole family, in a way, whether they're close together or far apart. So that's what kind of drives me to call people and be passionate about talking to people because I think of them as family members (Patient Navigator).

Staff providing outreach have also received annual training in motivational interviewing, social marketing and patient navigation to help increase their ability to convince patients to get screened and follow through with screening exams. Leadership and support at the highest level by the ANMC Chief of Surgery has also played a key role in the on-going vitality of the program.

Another element that benefits the program is that the Alaska Native population is an ethnic group that is geographically defined and a patient population that is well defined, unlike many other U.S. healthcare systems. There also exists a tribal health system responsibility to provide the best healthcare possible to this population, such that the FDR outreach is seen as a natural outgrowth of that obligation. Many regional tribal health organizations have also started to place a priority on CRC screening in general, which has made them more interested in getting their patient populations at increased risk (such as due to family history) screened.

Program barriers and challenges

The program outreaches to Alaska Native FDRs who come from diverse cultures throughout the state, and who may be at very different stages of behavior change and readiness to undergo screening. As mentioned previously responses can range from ready acceptance of the need for screening to anger and distrust, which can be a challenge to increasing screening in this population. Also, despite the increased education and awareness of CRC screening and prevention by Alaska Native people throughout the state, there are still misconceptions about screening; that it's either only for women or only for men, or that there is no need for screening if there are no physical signs and symptoms. Many Alaska Native people are unaware that FDRs are an increased risk sub-population within the larger Alaska Native population that experiences a significant health disparity due to CRC. Furthermore, due to some of the previous cultural barriers against mentioning the word cancer, some family members were unaware that their sibling or parent had cancer, or what type it was. Lack of discussion within families can

be a significant barrier to awareness of the important and need for screening. For Alaska Native people, additional barriers, including geographic distances and cost of travel may also play a role in CRC screening underutilization.

To be successful the program requires on-going identification of CRC patients, outreach to patients to obtain lists of their FDRs, database maintenance, and outreach to FDRs to promote screening. One key informant pointed to the on-going challenge of maintaining the database.

> I think that we don't really have a good way of cross [referencing]… one of the things is it's not integrated in our medical records system. So a patient may have had a procedure somewhere else, or they may have just had it done for diagnostic reasons by a surgeon, and we don't know that, and they're still in our database. So there's no real linkage to say, 'We don't need to screen this person anymore for another five years' (Clinician).

A further challenge is staff time. At various points in the implementation of the program the staff members responsible for family history outreach have had other clinical duties and so have not been able to devote attention to outreach activities. Furthermore, although the Alaska Area Native Health Service CRC Screening Guidelines (June, 2008) state that patients with two or more second-degree relatives should be screened starting at age 40, the program does not keep track of or outreach to second-degree relatives due to limitations in staff time. While the program has been successful at increasing outreach to FDRs, there are still many who have not been screened. Of the FDRs in the database due for screening, 44% have been screened. This is lower than the Alaska Native population average screening rate of 58.5%.[25] One key informant stated:

> The biggest challenge now is getting us up the next 20 percent. And that's going to take different approaches, whether that's different techniques of screening or making better use of the navigator program to do outreach […] Unless we do something different, we're going to stay where we are (Hospital Administrator).

A major challenge for the program mentioned by all key informants is the continued reliance upon grant and research (soft) money and the impact that may have on program sustainability.

> I've seen this many, many times in the Indian Health Service and now in the Alaska Native Health System is that when the grant for a program starts to shrink, the program also begins to shrink. And when the grant goes away, the program goes away and it has nothing to do with how important that program is to the health of the population or how successful the program is (Clinician).

Another issue identified is implementing a coordinated statewide focus, which is hampered by a lack of data sharing and reporting throughout the Alaska Tribal Health System. For example, the medical record information for FDRs who have completed screening at one of the regional facilities is not transmitted to ANMC and vice versa, such that a primary care provider at the regional facility might recommend screening not knowing that the patient was screened elsewhere, or the Alaska Native CRC Family Outreach Program database may show FDRs are due who have already been screened.

> Since it’s a huge state, a statewide program, I mean--and the colon cancers we’re getting now are not local people that have been screened before; they are way out there in rural communities. And so when we do get those family history lists, many times they have people on them, the first-degree relatives, who we know nothing about, medically. They may have not accessed the medical system. They may stay in their village or in a place where we don’t have access to their record [...] (Clinician).

There is also not any mechanism within the electronic medical record system for letting providers at regional facilities know about FDRs living in their region who are in need of screening, so that the FDRs could be screened more conveniently at their regional facility, other than the outreach lists compiled and distributed periodically to regional facilities by the Alaska Native CRC Family Outreach Program. More coordinated data

management and system efficiencies would improve the overall outreach to Alaska Native FDRs at risk for CRC. There also needs to be more coordination and education for providers and case managers so that they understand the importance of CRC screening for their increased-risk patients, and know the appropriate age to refer FDR patients in for screening. Primary care providers already have relationships built with their patients, and their recommendations could help improve screening adherence among this population.[26-31] One key informant noted:

> I think the education efforts are just--I mean they really set the stage for the navigators or for the primary-care people to be a success. So I think that all of the education stuff that's been done with the health aids, with the public, with the primary-care docs and things are just really, really important (Hospital Administrator).

Conclusions

It is vital that public health programs that seek to benefit Alaska Native people by reducing health disparities are evaluated. Evaluation allows for program improvement through assessment and modification. It allows for the results from successful programs to be promulgated for others to use as a basis for expanded efforts. It also builds the evidence base for emerging best practices. To the investigators' knowledge, the Alaska Native CRC Family Outreach Program is unique in the United States in its sustained gathering of information and outreach to FDRs of CRC patients, and is the only one of its kind for Alaska Native or American Indian people. There are some existing programs that provide outreach to family members of patients with HNPCC or FAP, and there has been an increased focus in the United States on CRC screening in the general population, most notably through the 25 state and four tribal Centers for Disease Control and Prevention-funded Colorectal Cancer Control Programs.[14] However, the national CRC Control Program focuses on average risk individuals, not those with an increased risk due to family history or personal history of CRC, and does not include systematic outreach to these increased-risk sub-populations.

Participatory research approaches provide a framework for increasing the cultural relevancy of evaluation of programs designed to improve the health of Native people, and have been further refined as the tribal participatory research model.[32-40] Along with the tribal participatory research model, this evaluation used an empowerment evaluation framework, which seeks to involve stakeholders throughout the evaluation process.[41] Representation from multiple groups of stakeholders, including clinical staff, program staff, and hospital leadership, helped make this process evaluation a strong and valuable source of information.

This qualitative study was undertaken to explore some of the initial factors that gave rise to the Alaska Native CRC Family Outreach Program, key elements of program success, and challenges to the continued growth and sustainability of the program. Process evaluation is a critical piece in determining whether a program has been implemented as conceived. It appears that the program design is well conceived and logically sound, and is being implemented as intended. However, full implementation took some time to develop, and the program did not hit full stride until the past two or three years when full-time funded patient navigators were able to devote dedicated time to the program activities. As a result of the process evaluation, five key components were identified including: program formation, program evolution, outreach responses, strengths of the program, and program barriers and challenges, which had a number of key themes within each component (see Table 4-1).

Within the program creation and implementation component, it was notable that an incremental approach, whereby the program came into being piece by piece, actually led to a well-developed program, despite not having been initiated as such. Indeed, there was no dedicated funding or staffing available in the earliest days of the program. However, the need was identified (Alaska Native FDRs at higher risk) and a clearly defined potential solution (collect contact information for FDRs and provide CRC screening

outreach to them). Based on those core activities the program was able to progressively grow and thrive. Within the outreach responses component, key themes include the increasing trend in CRC screening awareness among the Alaska Native population and the increasing number of Alaska Native FDRs screened for CRC. However, many FDRs report a range of responses which impact their participation in screening efforts. Within the successes and strengths component, a key theme was that having dedicated patient navigators was vital for increasing screening in this population, especially who are themselves Alaska Native, and so can provide more culturally competent outreach to the patients that they serve. Weaving through the strengths and successes component was the support for program activities exhibited by key leadership within the organization which was critical to the expansion of the program, along with successful attainment of program funding. However, within the barriers and challenges component, notable themes were the reliance on grant funding for program continuation, the need for dedicated staff time to perform outreach activities, the need for more provider education, and health system data access and coordination issues.

Several limitations of this study should be noted. Although the key findings can be used by other health organizations seeking to improve CRC screening outreach, especially for FDRs of CRC patients, due to the uniqueness of the Alaska Native CRC Family Outreach Program there was no comparison group to use to contrast with the activities and processes of the program. Also, creation of key components was conducted by one coder, although all interviews were audio recorded and two key informants were recontacted a week after the interview to reconfirm key points made during the interview.

Overall, this process evaluation provided a rich source of information on the development, successful components and strengths, and barriers and challenges of a program to increase CRC screening among Alaska Native FDRs of CRC patients. These findings have relevance for other programs and organizations working to increase health-seeking behaviors among populations experiencing significant health disparities.

Acknowledgements

Funding for this study was provided by the Centers for Disease Control and Prevention Division of Cancer Prevention and Control. We acknowledge the contributions and support of the Indian Health Service and the Alaska Native Tribal Health Consortium Board of Directors. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Literature Cited

1. Kelly JJ, Schade TL, Starkey BM, White S, Ashokkumar R, Lanier AP. Cancer in Alaska Native people: Forty year report 1969 – 2008. Anchorage, AK: Alaska Native Tumor Registry, Alaska Native Epidemiology Center, Alaska Native Tribal Health Consortium 2012.

2. SEER*Stat Database: Mortality - All COD, Aggregated With State, Total U.S. (1990-2007) <Katrina/Rita Population Adjustment> [database on the Internet]. National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch. 2011 [cited 5/12/2011]. Available from: www.seer.cancer.gov.

3. SEER*Stat Database: Incidence - SEER 13 Regs Research Data, Nov 2010 Sub (1992-2008) <Katrina/Rita Population Adjustment> - Linked To County Attributes - Total U.S., 1969-2009 Counties [database on the Internet]. National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch. 2011 [cited 5/12/2011]. Available from: www.seer.cancer.gov.

4. Smith RA, Cokkinides V, Eyre HJ. Cancer screening in the United States, 2007: a review of current guidelines, practices, and prospects. CA Cancer J Clin. 2007 Mar-Apr;57(2):90-104.

5. U.S. Preventive Services Task Force, Agency for Healthcare Research and Quality. Screening for colorectal cancer: recommendations and rationale. Rockville, MD 2002.

6. Fuchs, Giovannucci, Colditz, Hunter, Speizer, Willett W. A prospective study of family history and the risk of colorectal cancer. New England Journal Medicine. 1994;331(25):1669-74.

7. St John DJ, McDermott FT, Hopper JL, Debney EA, Johnson WR, Hughes ES. Cancer risk in relatives of patients with common colorectal cancer. Ann Intern Med. 1993 May 15;118(10):785-90.

8. Slattery ML, Kerber RA. Family history of cancer and colon cancer risk: the Utah Population Database. J Natl Cancer Inst. 1994 Nov 2;86(21):1618-26.

9. Boutron MC, Faivre J, Quipourt V, Senesse P, Michiels C. Family history of colorectal tumours and implications for the adenoma-carcinoma sequence: a case control study. Gut. 1995 Dec;37(6):830-4.

10. Pariente A, Milan C, Lafon J, Faivre J. Colonoscopic screening in first-degree relatives of patients with 'sporadic' colorectal cancer: a case-control study. The Association Nationale des Gastroenterologues des Hopitaux and Registre Bourguignon des Cancers Digestifs (INSERM CRI 9505). Gastroenterology. 1998 Jul;115(1):7-12.

11. Levin B, Lieberman DA, McFarland B, Smith RA, Brooks D, Andrews KS, et al. Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps, 2008: a joint guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology. CA Cancer J Clin. 2008 May-Jun;58(3):130-60.

12. Smith RA, Cokkinides V, Eyre HJ. American Cancer Society guidelines for the early detection of cancer, 2004. CA Cancer J Clin. 2004 Jan-Feb;54(1):41-52.

13. American Cancer Society. Colorectal Cancer Facts & Figures 2011-2013. Atlanta: American Cancer Society; 2011.

14. Joseph DA, DeGroff AS, Hayes NS, Wong FL, Plescia M. The Colorectal Cancer Control Program: partnering to increase population level screening. Gastrointest Endosc. 2011 Mar;73(3):429-34.

15. Redwood D, Joseph DA, Christensen C, Provost E, Peterson VL, Espey D, et al. Development of a flexible sigmoidoscopy training program for rural nurse practitioners and physician assistants to increase colorectal cancer screening among Alaska Native people. J Health Care Poor Underserved. 2009;20(4):1041-8.

16. Redwood D, Provost E, Perdue D, Haverkamp D, Espey D. The last frontier: innovative efforts to reduce colorectal cancer disparities among the remote Alaska Native population. Gastrointest Endosc. 2012 Mar;75(3):474-80.

17. Schumacher MC, Slattery ML, Lanier AP, Ma KN, Edwards S, Ferucci ED, et al. Prevalence and predictors of cancer screening among American Indian and Alaska Native people: the EARTH study. Cancer Causes Control. 2008 Sep;19(7):725-37.

18. Rossi P, Lipsey MW, Freeman HE. Evaluation. A systematic approach. Thousand Oaks, CA: Sage; 2004.

19. Harris MJ. Evaluating public and community health programs. San Francisco, CA: Jossey-Bass; 2010.

20. Dehar M-A, Casswell S, Duignan P. Formative and Process Evaluation of Health Promotion and Disease Prevention Programs. Evaluation Review. 1993 April 1, 1993;17(2):204-20.

21. Steckler A, Linnan L, . Process evaluation for public health interventions and research. San Francisco, CA: Josey-Bass; 2002.

22. Framework for program evaluation in public health. MMWR. 1999 Sep 17;48(RR-11):1-40.

23. Creswell JW, Plano Clark VL. Designing and conducting mixed methods research. Thousand Oaks, California: Sage Publications, Inc.; 2007.

24. Goodman L. Snowball sampling. Annuals Mathmatical Statistics. 1961;32(1):148-70.

25. IHS [Indian Health Service] 2012 Alaska Area GPRA [Government Performance and Results Act of 1993] Clinical Performance Report CCRS, Version 10.0. Alaska Area 2012 Aggregate Report. Anchorage, Alaska: Alaska Area Native Health ServiceReport run July 30, 2012.

26. Zlot AI, Silvey K, Newell N, Coates RJ, Leman R. Family history of colorectal cancer: clinicians' preventive recommendations and patient behavior. Prev Chronic Dis. 2012;9:E21.

27. Codori AM, Petersen GM, Miglioretti DL, Boyd P. Health beliefs and endoscopic screening for colorectal cancer: potential for cancer prevention. Prev Med. 2001 Aug;33(2 Pt 1):128-36.

28. Rawl SM, Menon U, Champion VL, May FE, Loehrer P, Sr., Hunter C, et al. Do benefits and barriers differ by stage of adoption for colorectal cancer screening? Health Educ Res. 2005 Apr;20(2):137-48.

29. Madlensky L, Esplen MJ, Gallinger S, McLaughlin JR, Goel V. Relatives of colorectal cancer patients: factors associated with screening behavior. Am J Prev Med. 2003 Oct;25(3):187-94.

30. Griffith KA, Passmore SR, Smith D, Wenzel J. African Americans with a family history of colorectal cancer: barriers and facilitators to screening. Oncol Nurs Forum. 2012 May 1;39(3):299-306.

31. Zlot AI, Cox SL, Silvey K, Leman R. The effect of chronic disease family history on healthcare provider practice and patient behavior among Oregonians. Public Health Genomics. 2012;15(3-4):189-200.

32. Cochran PA, Marshall CA, Garcia-Downing C, Kendall E, Cook D, McCubbin L, et al. Indigenous ways of knowing: Implications for participatory research and community. Am J Public Health. 2008 Jan;98(1):22-7.

33. Smith LT. Decolonizing methodologies: Research and indigenous peoples. New York: Zed Books; 1999.

34. Burhansstipanov L, Christopher S, Schumacher SA. Lessons learned from community-based participatory research in Indian country. Cancer Control. 2005 Nov;12 Suppl 2:70-6.

35. Holkup PA, Tripp-Reimer T, Salois EM, Weinert C. Community-based participatory research: an approach to intervention research with a Native American community. ANS Adv Nurs Sci. 2004 Jul-Sep;27(3):162-75.

36. Noe TD, Manson SM, Croy C, McGough H, Henderson JA, Buchwald DS. The influence of community-based participatory research principles on the likelihood of participation in health research in American Indian communities. Ethn Dis. 2007 Winter;17(1 Suppl 1):S6-14.

37. Chino M, Debruyn L. Building true capacity: indigenous models for indigenous communities. Am J Public Health. 2006 Apr;96(4):596-9.

38. Boyer BB, Mohatt GV, Pasker RL, Drew EM, McGlone KK. Sharing results from complex disease genetics studies: a community based participatory research approach. Int J Circumpolar Health. 2007 Feb;66(1):19-30.

39. Redwood D, Leston J, Asay E, Ferucci E, Etzel R, Lanier AP. Strategies for successful retention of Alaska Native and American Indian study participants. J Prim Prev. 2011 Feb;32(1):43-52.

40. Peterson JC. CBPR in Indian country: tensions and implications for health communication. Health Commun. 2010 Jan;25(1):50-60.

41. Fetterman DM. Empowerment evaluation: building communities of practice and a culture of learning. Am J Community Psychol. 2002 Feb;30(1):89-102.

CHAPTER 5

Colorectal cancer screening adherence among Alaska Native first-degree relatives of colorectal cancer patients[1]

Abstract

Background: Alaska Native (AN) people experience twice the incidence and mortality due to colorectal cancer (CRC) as U.S. Whites. CRC can be prevented through screening and early detection. First-degree relatives (FDRs: parents, siblings, children) of CRC patients are at increased risk and screening colonoscopy is recommended every five years starting at age 40.

Purpose: This study assessed screening adherence and outcomes among AN FDRs.

Methods: Review of a database of AN CRC patients and their FDRs containing information on demographic characteristics, screening adherence and outcomes.

Results: From January 1, 2000 to December 31, 2012, information on 691 CRC patients and 1979 of their FDRs (90 parents, 942 siblings, and 919 children) was compiled and used for screening outreach across the Alaska Tribal Health System. Over 80% of FDRs who had been screened were adherent to CRC screening guidelines. A total of 44% had been screened, compared to the AN population average of 58.5%. The advanced adenoma and adenocarcinoma detection rate was 34%. FDRs living in rural areas were significantly less likely to have been screened (38% vs. 59%, $p<0.001$). Children of CRC patients were more likely to have gotten screened than parents of CRC patients (46% vs. 30%, $p<0.05$) and younger FDRs were more likely to be adherent to current screening guidelines than older FDRs ($p<0.001$).

Conclusions: Preventing CRC among FDRs is vital. This study found an increase in AN FDR screening rates over the past ten years, corresponding with an increase in programmatic outreach to this increased risk population. Further research is needed to identify barriers and facilitators to CRC screening among Alaska Native people to reduce morbidity and mortality due to this disease.

[1]Redwood D, Provost E, Lopez E, Skewes M, Johnson R, Garcia G, Asay E, Sacco F, Espey E. Colorectal cancer screening adherence among Alaska Native first-degree relatives of colorectal cancer patients. Prepared for *American Journal of Preventive Medicine* 2013.

Background

In contrast to the declining United States (U.S.) death rate from cancer, the Alaska Native cancer death rate has not been declining.[1] For the period 2004-2008, the age-adjusted CRC mortality rate for Alaska Native people was nearly twice that of U.S. Whites (30.2 vs. 16.6 per 100,000). Alaska Native people also have about twice the incidence of CRC as U.S. Whites (97.2 vs. 50.1 per 100,000).[1] Furthermore, Alaska Native people experience the highest incidence rates of all American Indian groups compared to non-Hispanic Whites with the rate varying 5-fold between Alaska Native people and American Indian people from the Southwest U.S.[2-4]

Colorectal cancer can be treated or prevented if detected early through the use of screening tests, including colonoscopy, flexible sigmoidoscopy, and fecal occult blood tests.[5, 6] Because of the disproportionate burden of CRC among Alaska Native people, it is important to identify those at highest risk and encourage them to receive appropriate screening.[2] Family history is a critical component of CRC risk stratification.[7-9] People with a family history of CRC or adenomatous polyps in one or more first-degree relatives (FDRs; parents, siblings, or children) are at almost twice the risk for CRC.[7, 8, 10, 11] A prospective study of participants in the Nurses' Health Study and the Health Professionals Follow-up Study found that FDRs of CRC patients had a 1.7-fold increase in risk of CRC.[12] Furthermore, for persons who had two or more affected FDRs or who were younger than age 44 the relative risk increased substantially.[12] This association held even after adjustment for other known or suspected risk factors for CRC.[7] A total of 10% to 30% of cases of CRC occur in people who have a relative with a history of an adenomatous polyp or CRC. This family history may increase CRC risk by influencing adenoma formation or enhancing the formation of new lesions.[13]

FDRs of CRC patients are the largest groups of individuals at increased CRC risk. Overall, it is believed that screening strategies targeting FDRs of affected cases could contribute to the prevention or early detection of 15% to 20% of CRCs.[14, 15] Therefore,

FDRs are an increased risk sub-population within the larger Alaska Native population that experiences a significant health disparity due to CRC. Based on national guidelines,[16, 17] the Alaska Tribal Health System CRC screening guidelines (June 2008) recommend that Alaska Native people with a first-degree relative or two or more second-degree relatives receive a colonoscopy every five years beginning at age 40 or ten years before the youngest diagnosed family member, whichever occurs earlier.

CRC screening rates among the Alaska Native population are lower than U.S. White rates, but have been steadily increasing, from 29.0% in 2000 to 58.5% in 2012 of age-appropriate Alaska Native people being up to date with CRC screening (colonoscopy in last 10 years or flexible sigmoidoscopy in last 5 years).[18] Data from the Alaska Behavioral Risk Factor Surveillance System (BRFSS) in 2011 showed that 68.1% of Alaska Native adults reported ever having a sigmoidoscopy or colonoscopy. This screening rate was a notable increase from 50.0% in 2010 and 51.8% in 2008. The 2011 rate is the first time that the Alaska Native rate has been above the rate for all Alaskans or Alaska Whites (65.0%).[19] Through substantial efforts, CRC screening rates among Alaska Native people are close to the Healthy People 2020 target (70.5%) but are still below the CDC National CRC Control Program 2014 goal of 80%.[20] Additionally, statewide aggregated rates hide the wide variation in CRC screening by tribal health region, which varies from 30% to 72% statewide.[18]

Although no statewide data are available on family history of CRC in Alaska, data from a supplemental questionnaire included in the 2008 Oregon BRFSS found that 8% of respondents reported having a FDR with CRC.[21] In Alaska, the only published data available on Alaska Native family history of CRC comes from the Alaska Education and Research Towards Health (EARTH) Study, which found a total of 13% of Alaska EARTH Study participants (2004-2006) reported one or more FDRs diagnosed with CRC.[22] Of those who knew the age of diagnosis of their relative (n=209), 38% reported that their family member was diagnosed with CRC before age 50.[23] Study participants

who reported a family history of CRC were twice as likely to report receipt of a colonoscopy or flexible sigmoidoscopy in the past five years (44.1% vs. 26.2%).[24] However, this still represents a low screening rate for a population at increased risk.

In 1997, the Alaska Native Tribal Health Consortium (ANTHC), a statewide non-profit health services organization owned and operated by Alaska Native people was formed to provide health services to members of the 229 tribes throughout Alaska and support the tribal health organizations that comprise the Alaska Tribal Health System (ATHS). The Alaska Tribal Health System is a spoke-and-hub system consisting of small tribal village clinics, sub-regional clinics, and regional hospitals, with one tertiary care hospital (Alaska Native Medical Center, ANMC) in Anchorage. The size and geography of Alaska can present formidable barriers to obtaining healthcare, including cancer screening. In 2004, ANMC hospital administrators decided to start collecting FDR contact information from CRC patients treated at ANMC. These patients are approached for a contact list of their FDRs either while still in the hospital, when coming back for follow-up appointments or via a form sent with a business reply envelope to their home. The FDR contact information is entered into a computerized Microsoft Access database. Direct outreach using a CRC screening patient navigation began in 2007. In 2012, another patient navigator was added to the program, which greatly increased the number of FDRs screened (see Figure 5-1). The patient navigators provide direct outreach (phone calls, mailed letters, and one-on-one interactions) to encourage CRC screening among Alaska Native family members who receive care in the Anchorage area. Lists of FDRs living in other parts of the state in need of screening are also sent annually to regional tribal Medical and Clinical Directors for outreach efforts. Defined familial syndromes associated with extremely high risks of CRC, such as hereditary non-polyposis colorectal syndrome (HNPCC) or familial adenomatous polyposis (FAP),[25] require and receive specialized case management services at ANMC.

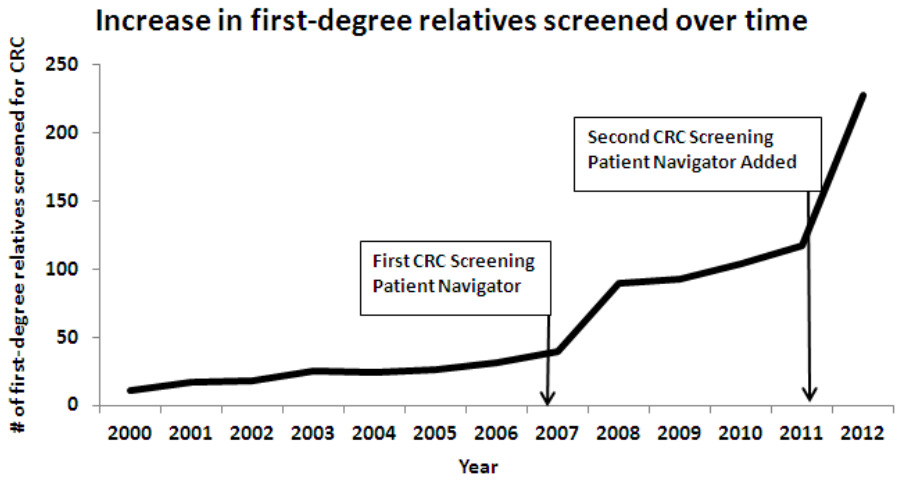


Figure 5-1. Impact of CRC screening patient navigators on number of first-degree relatives screened, Alaska Native Colorectal Cancer Family Outreach Program, 2000-2012.

The purpose of this study was to examine the prevalence of screening adherence among Alaska Native FDRs of CRC patients, and characteristics associated with screening patterns in this increased-risk population. The Alaska Area Institutional Review Board (IRB), the University of Alaska Fairbanks and the Alaska Native Tribal Health Consortium and Southcentral Foundation research and ethics committees as well as the relevant tribal privacy officers reviewed and approved the study protocol. It was also approved for clearance by the Centers for Disease Control and Prevention Division of Cancer Prevention and Control, which funded the study.

Methods

Screening outcomes data were entered into the FDR database from medical records and combined with outreach data included in the FDR database for the study analysis. Summary statistics were calculated to provide an overview of Alaska Native CRC patients and their FDRs. The demographic variables analyzed for CRC patients included: sex, age at CRC diagnosis, and year of CRC diagnosis. FDR characteristics analyzed included age, relationship (parent, sibling child), screening status, screening type, and resident community size (urban area was based on 2010 U.S. Census definition of a

population of 50,000 or greater). Analysis of years since colorectal screening, screening adherence by region and screening adherence by relationship were restricted to those FDRs who were currently alive. Statistical software (SPSS for Windows, Version 16.0 Chicago, Illinois, 2007) was used to analyze quantitative data (frequencies, chi-square tests of association, linear regression). All analyses were 2-tailed, and significance was set at $p<0.05$.

Results

Between January 1, 2000 and December 31, 2012, there were 691 CRC patients (52% women) included in the program database, along with 1,979 FDRs (see Table 5-1). Of the 1,951 FDRs for whom the relationship was specified, 90 (5%) were parents, 942 (48%) were siblings, and 919 (47%) were children. On average about 3 FDRs were identified per CRC patient, and the mean age of CRC diagnosis was 61.7 years old (range 20-94). Since the project began only 9 (1%) CRC patients have declined to give contact information for their FDRs, although 95 CRC patients were lost to follow-up and thus had no relatives listed for them (data not shown). Case ascertainment for CRC patients was very high; of the 53 newly diagnosed CRC patients at ANMC in 2012, 45 (89%) were in the program database. The FDR mean age was 53.1 years old (range 3 to 98), and the mean age due for screening was 38.3 years old (range 11 to 40). Over 80% of FDRs were at or over age 40.

Table 5-1. Alaska Native colorectal cancer patient and first-degree relative demographic characteristics, 2000-2012.

Characteristic	No. (%)
CRC Patients	**691 (100)**
Female	359 (52)
Deceased	249 (36)
Age at diagnosis (mean) (range: 20-94)	61.7
Diagnosis year	
Pre-1999	166 (24)
2000-2009	361 (52)
2010-2012	164 (24)
First-degree Relatives (FDRs)	**1979 (100)**
Relationship (n=1951)	
Parent	90 (5)
Sibling	942 (48)
Child	919 (47)
Age, years (n=1890)	
Mean age (range: 3-98)	53.1
Mean age due screening (range: 11-40)	38.3
<40	374 (20)
≥40	1516 (80)

As shown in Table 5-2, 319 (18%) of FDRs were not due for screening yet (too young), 637 (36%) were screened previously by flexible sigmoidoscopy or colonoscopy, and 820 (46%) were due for screening. A total of 824 FDRs had ever received a CRC screening exam of any type, 95% of which were colonoscopies. Of the living FDRs screened by colonoscopy for whom screening date was recorded (n=781), the majority (80%) were adherent to screening guidelines (screened by colonoscopy within the last 5 years), an additional 12% had been screened between 6 to 9 years prior, and 8% had been screened 10 or more years prior. There was a significant difference in screening status by rural or urban community (38% vs. 59%, chi-square=57.68, df=1, $p<0.001$) as well as by familial relationship. Children of CRC patients were much more likely to have gotten screened than parents (46% vs. 30%, chi-square=5.65, df=1, $p<0.05$). Additionally, among FDRs who had already been screened, younger FDRs were more likely to be adherent to current screening guidelines than older FDRs (t= -7.79, df=3, $p<0.001$) and children (87%) were

more likely to be adherent than siblings (76%) or parents (61%) (chi-square=19.17, df=2, $p<0.05$).

Table 5-2. Alaska Native colorectal cancer first-degree relative screening outcomes, 2000-2012.

Characteristic	No. (%)
First-degree Relatives (FDRs)	**1979 (100)**
Screening status (n=1776)	
Too young	319 (18)
Screened by flexible sigmoidoscopy or colonoscopy	637 (36)
Due for screening	820 (46)
Screening type, ever had (n=824)	
Barium enema	4 (1)
Flexible sigmoidoscopy	33 (4)
Colonoscopy	787 (95)
Screening by colonoscopy, years (n=781)	
≤5	622 (80)
6-9	94 (12)
≥10	65 (8)
Screening adherence by region (% screened)*	
Rural	363 (38)
Urban	252 (59)
Screening adherence by relationship (% screened)	
Parent	20 (30)
Sibling	340 (42)
Child	257 (46)
Screening adherence to guidelines by relationship (% screened)*	
Parent	20 (61)
Sibling	340 (76)
Child	257 (87)
Screening histology (n=788)	
Normal, non-polyp, or non-adenomatous polyps	424 (54)
Hyperplastic polyps	97 (12)
Adenomas, not otherwise specified	31 (4)
Tubular adenomas	159 (20)
Tubulovillous, villous or serrated adenomas	41 (5)
Adenocarcinomas or adenomas with high grade dysplasia	36 (5)

*$p<0.05$.

Note: All shaded categories were considered advanced neoplasia.

Of the 788 (95%) persons screened for whom results were available, 54% had normal or non-adenomatous polyp histology, 12% had hyperplastic polyps, 4% had adenomas of unknown type, 20% had tubular adenomas, 5% had tubulovillous, villous or serrated adenomas, and 5% had adenocarcinomas or adenomas with high grade dysplasia. The overall adenoma detection rate was 34%.

Discussion

This study is the first examination of CRC screening adherence and characteristics among Alaska Native FDRs of CRC patients. The results showed that the number of Alaska Native FDRs screened for CRC increased significantly over the past decade. However, only 44% of FDRs due had been screened. This is lower than the Alaska Native population average screening rate of 58.5%.[18] An encouraging finding was among FDRs screened, 80% were adherent to current guidelines (colonoscopy within the past 5 years). U.S. screening rates among FDRs have increased over the past decade. According to the National Health Interview Survey (2005), CRC screening (endoscopy) had increased to 65% among those with a family history. However, only participants over age 50 were asked their screening history, which may over represent the true screening rate among FDRs, many of whom need to be screened at much earlier ages when they may not be aware of the need for screening.[26] In the current study the adenoma detection rate among Alaska Native FDRs was 34%, which is much higher than a national study of Medicare beneficiaries (24%).[27]

Despite the number of published recommendations for screening individuals at increased risk of CRC due to their family history, a review by Rees et al. (2008) found few studies that had specifically investigated screening adherence patterns among FDRs.[28] In this study of Alaska Native FDRs, adherence to current screening guidelines was higher among urban Alaska Native populations than rural FDRs. Of the FDRs due for screening known to be living in Alaska, the majority (78%) were located in rural areas, which may reflect the challenges of access to higher levels of health services. This finding warrants

further investigation. This study also found that younger FDRs and FDRs who were children of CRC patients were more likely to have gotten screened and to be up-to-date with screening. These results are consistent with some studies which found that younger cohorts were more likely to obtain screening by colonoscopy than older cohorts.[29] Yet, other studies have reported higher screening uptake among older FDRs,[30-32] and some have reported no association between FDR age and screening behavior.[33]

There are several theoretical constructs that may influence CRC screening behavior, including perceived susceptibility, self-efficacy, and social influence.[34, 35] For Alaska Native people, additional barriers, including geographic distances and cost of travel may also play a role in underutilization of CRC screening. In recent years there has been a national trend towards use of patient navigation for CRC screening promotion to help address barriers to screening.[36, 37] CRC screening patient navigation provides individualized assistance to help overcome healthcare system and patient-level barriers to care and helps guide individuals into action.[36] The Alaska Native Colorectal Cancer Family Outreach Program works to increase screening among FDRs by sending mailed reminder letters and making phone calls to encourage FDRs to get CRC screening, as well as using face-to-face approaches.[37] To the investigators knowledge this sort of sustained outreach to increased risk family members of CRC patients is unique in the United States, and is the only one of its kind for Alaska Native or American Indian people. An informal survey of FDR outreach among the 25 state and four tribal Centers for Disease Control and Prevention-funded Colorectal Cancer Control Programs resulted in responses from six states and one tribe. One state reported that their results letter sent to patients identified with CRC or adenomatous polyps includes a sentence encouraging the patient to notify their FDRs that they are also at increased risk for CRC and polyps and to consult their primary care physicians regarding screening colonoscopy. However, none of the respondents reported that they provide active outreach to family members of CRC patients, nor did any program managers know of other programs doing such outreach. One way to more sustainably conduct FDR outreach would be to have family

member name, date of birth and contact information included in central cancer tumor registries for patients with confirmed CRC diagnoses. This information could then be used for outreach by CRC prevention programs to promote screening among this increased-risk population.

Several limitations and strengths of this study should be emphasized. One limitation of this study is that colonoscopic results among FDRs in the program were limited to the most recent exam, and do not include prior abnormal findings. Therefore, a FDR could have had CRC or advanced polyps on a previous exam, but the results of the five-year surveillance colonoscopy were normal, which therefore may have led to an underestimation of the true adenomatous polyp detection rate. A retrospective medical record review would be necessary to more accurately categorize these patients on the basis of total clinical findings. Additionally, FDRs could have been screened outside of the Alaska Tribal Health System (ATHS), and thus the FDR screening rate presented here may be lower than the true prevalence. However, efforts were made to elicit information from FDRs as to prior screenings whenever possible, and CRC screening is a fully covered benefit for Alaska Native beneficiaries who receive their care within the ATHS. Lastly, the study sample was not able to be restricted to asymptomatic patients, thus patients may have been screened for diagnostic, not screening purposes. A strength of the study was that family history and screening test type and adherence to interval guidelines were objectively assessed through use of ATHS medical records, instead of relying on retrospective self-reports of screening behavior and family history.[28, 38]

In summary, the available evidence suggests that screening rates of Alaska Native FDRs of CRC patients in accordance with guideline recommendations is increasing but remain lower than would be optimal to reduce CRC incidence and mortality on a population level. First-degree family members are an increased risk population, within a larger Alaska Native population that experiences nearly twice the incidence and mortality due to CRC as the U.S. White population. Further research is needed to inform interventions to

support sustained screening participation in this population and help reduce morbidity and mortality due to this disease.

Acknowledgements

Funding for this study was provided by the Centers for Disease Control and Prevention Division of Cancer Prevention and Control. We acknowledge the contributions and support of the Indian Health Service and the Alaska Native Tribal Health Consortium Board of Directors. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Literature Cited

1. Kelly JJ, Schade TL, Starkey BM, White S, Ashokkumar R, Lanier AP. Cancer in Alaska Native people: Forty year report 1969 – 2008. Anchorage, AK: Alaska Native Tumor Registry, Alaska Native Epidemiology Center, Alaska Native Tribal Health Consortium 2012.

2. Perdue D.G., Perkins C., Jackson-Thompson J., Coughlin S.S., Ahmed F., Haverkamp D.S., et al. Regional differences in colorectal cancer incidence, stage, and subsite among American Indians and Alaska Natives, 1999-2004. Cancer. 2008 Sep 1;113(5 Suppl):1179-90.

3. Espey D, Paisano R, Cobb N. Regional patterns and trends in cancer mortality among American Indians and Alaska Natives, 1990-2001. Cancer. 2005 Mar 1;103(5):1045-53.

4. Espey DK, Wu XC, Swan J, Wiggins C, Jim MA, Ward E, et al. Annual report to the nation on the status of cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. Cancer. 2007 Nov 15;110(10):2119-52.

5. Smith RA, Cokkinides V, Eyre HJ. Cancer screening in the United States, 2007: a review of current guidelines, practices, and prospects. CA Cancer J Clin. 2007 Mar-Apr;57(2):90-104.

6. U.S. Preventive Services Task Force, Agency for Healthcare Research and Quality. Screening for colorectal cancer: recommendations and rationale. Rockville, MD 2002.

7. Fuchs, Giovannucci, Colditz, Hunter, Speizer, Willett W. A prospective study of family history and the risk of colorectal cancer. New England Journal Medicine. 1994;331(25):1669-74.

8. Screening for colorectal cancer: U.S. Preventive Services Task Force recommendation statement. Ann Intern Med. 2008 Nov 4;149(9):627-37.

9. Butterworth AS, Higgins JP, Pharoah P. Relative and absolute risk of colorectal cancer for individuals with a family history: a meta-analysis. Eur J Cancer. 2006 Jan;42(2):216-27.

10. St John DJ, McDermott FT, Hopper JL, Debney EA, Johnson WR, Hughes ES. Cancer risk in relatives of patients with common colorectal cancer. Ann Intern Med. 1993 May 15;118(10):785-90.

11. Slattery ML, Kerber RA. Family history of cancer and colon cancer risk: the Utah Population Database. J Natl Cancer Inst. 1994 Nov 2;86(21):1618-26.

12. Fuchs CS, Giovannucci EL, Colditz GA, Hunter DJ, Speizer FE, Willett WC. A prospective study of family history and the risk of colorectal cancer. N Engl J Med. 1994 Dec 22;331(25):1669-74.

13. Wark PA, Wu K, van 't Veer P, Fuchs CF, Giovannucci EL. Family history of colorectal cancer: a determinant of advanced adenoma stage or adenoma multiplicity? Int J Cancer. 2009 Jul 15;125(2):413-20.

14. Boutron MC, Faivre J, Quipourt V, Senesse P, Michiels C. Family history of colorectal tumours and implications for the adenoma-carcinoma sequence: a case control study. Gut. 1995 Dec;37(6):830-4.

15. Pariente A, Milan C, Lafon J, Faivre J. Colonoscopic screening in first-degree relatives of patients with 'sporadic' colorectal cancer: a case-control study. The Association Nationale des Gastroenterologues des Hopitaux and Registre Bourguignon des Cancers Digestifs (INSERM CRI 9505). Gastroenterology. 1998 Jul;115(1):7-12.

16. Levin B, Lieberman DA, McFarland B, Smith RA, Brooks D, Andrews KS, et al. Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps, 2008: a joint guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology. CA Cancer J Clin. 2008 May-Jun;58(3):130-60.

17. Smith RA, Cokkinides V, Eyre HJ. American Cancer Society guidelines for the early detection of cancer, 2004. CA Cancer J Clin. 2004 Jan-Feb;54(1):41-52.

18. IHS [Indian Health Service] 2012 Alaska Area GPRA [Government Performance and Results Act of 1993] Clinical Performance Report CCRS, Version 10.0. Alaska Area 2012 Aggregate Report. Anchorage, Alaska: Alaska Area Native Health ServiceReport run July 30, 2012.

19. Alaska Department of Health and Social Services. Alaska Behavioral Risk Factor Surveillance System. Juneau, AK: Alaska Department of Health and Social Services 2011.

20. Joseph DA, DeGroff AS, Hayes NS, Wong FL, Plescia M. The Colorectal Cancer Control Program: partnering to increase population level screening. Gastrointest Endosc. 2011 Mar;73(3):429-34.

21. Zlot AI, Silvey K, Newell N, Coates RJ, Leman R. Family history of colorectal cancer: clinicians' preventive recommendations and patient behavior. Prev Chronic Dis. 2012;9:E21.

22. Lanier AP, Redwood DG, Kelly JJ. The Alaska Education and Research Towards Health (EARTH) Study: Cancer Risk Factors. J Cancer Educ. 2012 Feb 2.

23. Slattery ML, Murtaugh MA, Lanier AP, Ma KN, Ferucci ED, Etzel RA, et al. Family health history and health behaviors in Alaska Native and American Indian people. J Health Care Poor Underserved. 2009 Aug;20(3):678-94.

24. Schumacher MC, Slattery ML, Lanier AP, Ma KN, Edwards S, Ferucci ED, et al. Prevalence and predictors of cancer screening among American Indian and Alaska Native people: the EARTH study. Cancer Causes Control. 2008 Sep;19(7):725-37.

25. American Cancer Society. Colorectal Cancer Facts & Figures 2011-2013. Atlanta: American Cancer Society; 2011.

26. Shapiro JA, Seeff LC, Thompson TD, Nadel MR, Klabunde CN, Vernon SW. Colorectal cancer test use from the 2005 National Health Interview Survey. Cancer Epidemiol Biomarkers Prev. 2008 Jul;17(7):1623-30.

27. Cooper GS, Chak A, Koroukian S. The polyp detection rate of colonoscopy: a national study of Medicare beneficiaries. The American journal of medicine. 2005 Dec;118(12):1413.

28. Rees G, Martin PR, Macrae FA. Screening participation in individuals with a family history of colorectal cancer: a review. Eur J Cancer Care (Engl). 2008 May;17(3):221-32.

29. Bleiker EM, Menko FH, Taal BG, Kluijt I, Wever LD, Gerritsma MA, et al. Screening behavior of individuals at high risk for colorectal cancer. Gastroenterology. 2005 Feb;128(2):280-7.

30. Codori AM, Petersen GM, Miglioretti DL, Boyd P. Health beliefs and endoscopic screening for colorectal cancer: potential for cancer prevention. Prev Med. 2001 Aug;33(2 Pt 1):128-36.

31. Madlensky L, Esplen MJ, Gallinger S, McLaughlin JR, Goel V. Relatives of colorectal cancer patients: factors associated with screening behavior. Am J Prev Med. 2003 Oct;25(3):187-94.

32. Shvartzman P, Rivkind E, Neville A, Friger M, Sperber AD. Screening intention and practice among first-degree relatives of colorectal cancer patients in southern Israel. Isr Med Assoc J. 2000 Sep;2(9):675-8.

33. Richardson JL, Danley K, Mondrus GT, Deapen D, Mack T. Adherence to screening examinations for colorectal cancer after diagnosis in a first-degree relative. Prev Med. 1995 Mar;24(2):166-70.

34. Mack LA, Cook LS, Temple WJ, Carlson LE, Hilsden RJ, Paolucci EO. Colorectal cancer screening among first-degree relatives of colorectal cancer patients: benefits and barriers. Ann Surg Oncol. 2009 Aug;16(8):2092-100.

35. Vernon SW, Myers RE, Tilley BC. Development and validation of an instrument to measure factors related to colorectal cancer screening adherence. Cancer Epidemiol Biomarkers Prev. 1997 Oct;6(10):825-32.

36. Myers RE, Hyslop T, Sifri R, Bittner-Fagan H, Katurakes NC, Cocroft J, et al. Tailored navigation in colorectal cancer screening. Med Care. 2008 Sep;46(9 Suppl 1):S123-31.

37. Dignan MB, Burhansstipanov L, Hariton J, Harjo L, Rattler T, Lee R, et al. A comparison of two Native American Navigator formats: face-to-face and telephone. Cancer Control. 2005 Nov;12 Suppl 2:28-33.

38. Ruthotto F, Papendorf F, Wegener G, Unger G, Dlugosch B, Korangy F, et al. Participation in screening colonoscopy in first-degree relatives from patients with colorectal cancer. Ann Oncol. 2007 Sep;18(9):1518-22.

CHAPTER 6

Conclusions

Alaska Native (AN) people experience twice the incidence and mortality due to colorectal cancer (CRC) as U.S. Whites. CRC can be prevented through screening and early detection. Besides age, family history of CRC is a key risk factor in CRC pathogenesis, with first-degree relatives (FDRs: parents, siblings, children) of CRC patients experiencing twice the risk as the general population. Therefore, FDRs are an increased risk sub-population within the larger Alaska Native population that experiences a significant health disparity due to CRC. Improving outreach to persons at increased risk of CRC because of their family history is critical to efforts to reduce CRC morbidity and mortality. This can be especially challenging in the Alaska healthcare setting, which requires Alaska Native patients seeking CRC screening to travel far distances involving airplane flights, out of town stays, and weather-related travel delays.

Despite the number of published recommendations for screening individuals at increased risk of CRC due to their family history, there are few studies that have specifically investigated screening adherence patterns among FDRs, and none have explored CRC screening trends and characteristics among Alaska Native FDRs.[1] Use of active outreach to encourage CRC screening among FDRs is likewise rare to non-existent in the U.S., and no data exist on the extent and types of outreach occurring for this sub-population within the Alaska Tribal Health System (ATHS).

This study assessed the prevalence of CRC screening outreach to FDRs at Alaska regional tribal health organizations (THOs), use of family history information, barriers to CRC screening, and potential tools to improve CRC screening throughout the Alaska Tribal Health System (ATHS). The study also included a process and outcome evaluation of the Alaska Native Colorectal Cancer Family Outreach Program, which encourages

CRC screening among Alaska Native FDRs of CRC patients. The process evaluation included a qualitative study of themes related to the program using key informant interviews and program document review. The outcome evaluation included an examination of the prevalence of screening adherence among Alaska Native FDRs of CRC patients, and characteristics associated with screening patterns in this increased-risk population.

The main empirical findings are chapter specific and were summarized within the respective empirical chapters: “Use of Family History for Colorectal Cancer Outreach in the Alaska Tribal Health System,” “A Process Evaluation of the Alaska Native Colorectal Cancer Family History Outreach Program,” and “Colorectal Cancer Screening Adherence among Alaska Native First-degree Relatives of Colorectal Cancer Patients”. The survey of CRC screening outreach at ATHS facilities study found that CRC screening outreach is common in the ATHS, with over 90% of tribal health organizations surveyed reporting providing at least some sort of CRC screening outreach to patients. However, significant barriers still exist, especially for outreach to FDRs, for which only half of survey respondents (50%) said they do any sort of outreach to encourage screening among FDRs, and only half (50%) had a mechanism for keeping track of family history in the facility medical record system. Patient level barriers to screening were also noted, including a lack of awareness of the benefits and importance of screening, especially among patients who are healthy and who don’t often access the medical system. Respondents felt that more Alaska Native-specific health education materials and training for ATHS healthcare providers on screening guidelines would help increase CRC screening and referrals. The most significant challenge cited among all respondents was lack of time, resources and dedicated personnel.

The Alaska Native Colorectal Cancer Family Outreach Program process evaluation elicited information within a number of themes, including program formation, evolution, outreach responses, strengths, and barriers and challenges. Key findings included an

incremental approach which led to a fully formed program and the need for dedicated culturally competent patient navigation. Challenges identified included differing FDR responses to screening outreach, health system data access and coordination, challenges in maintaining dedicated staff time to the program, and the use of grant funding for program operations. The Alaska Native Colorectal Cancer Family Outreach Program outcome evaluation found despite increasing programmatic outreach and FDR screening rates, a large proportion of Alaska Native FDRs were still due for screening (56%). Screening adherence was significantly lower among Alaska Native FDRs living in rural/remote areas compared with urban areas (38% screened vs. 59%, chi-square=57.68, df=1, $p<0.001$) as well as older Alaska Native FDRs compared with younger FDRs ($t= -7.79$, df=3, $p<0.001$). However, of FDRs who had been screened, the majority (80%) were adherent to currently recommended interval guidelines (colonoscopy every five years). In summary, the study data suggest that screening rates of Alaska Native FDRs of CRC patients in accordance with guideline recommendations are increasing but remain much lower than would be optimal to reduce CRC incidence and mortality on a population level.

Study Implications

The results of this study have a number of policy and research implications. In the framework of the social ecological model, these results point to three avenues along which to approach increasing Alaska Native CRC screening, especially among FDRs. On the Interpersonal level, there is a need for culturally competent CRC screening outreach by medical paraprofessionals, such as patient navigators, as well as an expansion of training opportunities for all healthcare providers in use of appropriate screening referral guidelines. On the Organizational level, improving ATHS electronic medical records systems to facilitate CRC screening reminders and coordination is needed. On the Policy level, expansion is needed in the resources devoted to CRC screening beyond the current substantial reliance on grant funding to support outreach activities. Specific activities for implementing these recommendations are detailed below.

The ATHS is made up of multiple regional THOs, all of whom are dedicated to improving cancer prevention and care for the patients that they serve. In recent years there has been a national trend towards use of patient navigation to improve patient adherence to screening guidelines and assist patients with barriers to screening. Grants for improving CRC screening in the ATHS have led to the creation and staffing of CRC screening patient navigator or equivalent positions in nine of the 17 main regional THOs. These patient navigators provide screening outreach to patients and help decrease behavioral and structural barriers to screening.[2-7] However, much remains unclear as to the best ways to implement patient navigation in tribal health settings, and how best to train navigators to provide culturally competent care.[8]

Additionally, although provider recommendation has been found across studies to be a major facilitator of screening adherence,[9, 10] surveys and claims data analysis of tribal and non-tribal healthcare providers find that knowledge gaps exist regarding the appropriate age to initiate screening, appropriate use of tests, and appropriate time intervals to repeat screening.[11, 12] This is especially important for FDRs, who need to be screened earlier than the average-risk population, and with colonoscopy rather than other screening methods. Evaluation research is needed on the most effective ways to communicate screening guidelines to tribal providers and how to help them encourage screening referrals in their tribal health practice, for example by adapting national clinician toolkits[13] for the Alaskan setting.

Electronic medical records systems that do not facilitate CRC screening were also noted throughout this study as a barrier to more systematic CRC screening outreach. Alaska, like the rest of the United States, faces challenges in addressing increasing healthcare costs, improving access to medical care, and ensuring and improving quality medical care for patients. Timely access to essential medical information by providers at the point of care is critical to good outcomes for the patients and to improving quality and

coordination of patient care. Many studies, as well as the USPSTF guidelines, demonstrate strong evidence for use of provider reminder systems to improve screening rates.[14-16] Computerized health records have a long history in the ATHS. Each THO maintains health records for users of their system. The majority of these health record systems are electronic, which has the potential for increasing provider ability to note family history in the medical record and use it for outreach to family members. However, this study found that systematic outreach using electronic health records as a tool was rare to non-existent in the ATHS, especially for FDRs. Previously one main electronic health record, the Indian Health Service Resource and Patient Management System (RPMS) was used within the ATHS, but over the last decade regional THOs have moved to using multiple electronic health records systems, which do not interface with one another and which are not consistent in where family history and previous cancer screening information is located within the medical record. Policy changes are needed at the tribal health organizational level to improve the use of electronic medical records systems for coordinated and efficient CRC screening and outreach within the ATHS. This could potentially include data sharing agreements among regional THOs to better organize the flow of screening and outcomes data across the entire ATHS. Another potential area for policy development is to include family member names, dates of birth and contact information in central cancer tumor registries for patients with confirmed CRC diagnoses. This information could then be used for FDR screening outreach by CRC prevention programs. Research in developing innovative provider and health system approaches in the ATHS is vital for improving CRC screening delivery, as well as follow-up care and cancer surveillance.

Perhaps not surprisingly, uncertain funding and lack of dedicated resources and staff was an area noted throughout the study, especially in regards to future sustainability of CRC screening activities. The Alaska Native CRC Family Outreach Program is unique in its efforts to identify Alaska Native FDRs and provide patient navigation to guide them into appropriate CRC screening and follow-up. However, these activities are entirely grant-

driven, which means that if future grants are not secured, this outreach activity will cease. In other areas, notably in New York, a pilot patient navigator program in urban public hospitals was evaluated for cost, cost-effectiveness, and cost-benefit analyses. The economic evaluation found that overall the program was cost-effective and actually yielded a net financial benefit, primarily through decreasing patient broken appointment rates, which increased overall colonoscopy volume,[7, 17] and by improving patient bowel preparation quality, which reduced the number of colonoscopies that needed to be repeated.[3] The results of the study were used to encourage hospitals to hire and train patient navigators as part of standard hospital operating costs. This type of economic analysis has never been conducted on patient navigation in Alaskan healthcare settings. Conducting economic analysis research in the tribal health setting could provide data for building the business case for adding patient navigation to the menu of healthcare delivery services that are currently provided in the ATHS.

Some limitations of this study should be noted. No data were available on the sex of Alaska Native FDRs included in the Alaska Native CRC Family Outreach Program; therefore it was not possible to determine if there were differences between men and women in FDR screening behaviors. This study may also have underrepresented the true screening prevalence of Alaska Native FDRs as some patients may have been screened outside of the Alaska Tribal Health System (ATHS). However, efforts were made to elicit information from FDRs as to all prior screenings whenever possible, and CRC screening is a fully covered benefit for Alaska Native beneficiaries who receive their care within the ATHS. Additionally, although Alaska Native FDR screening rates increased over the years of the program, overall screening rates in the Alaska Native population were also increasing over the same period, thus it is not possible to attribute positive screening trends just to program outreach activities. Further research is needed to more fully explore screening characteristics, barriers, and facilitators to screening in this increased-risk population.

Another issue is that much of the study data was qualitative in nature, derived primarily from key informant interviews and document review. These data provided a rich source of information, especially in regards to outreach activities across the ATHS and the formation, successes and challenges of the Alaska Native CRC Family Outreach Program. There are however, disadvantages to this type of research, including small study sample size and corresponding implications for study validity and reliability.[18] A snowball sampling technique was used to identify as many stakeholder perspectives as possible for both the ATHS interviews as well as the Alaska Native CRC Family Outreach Program interviews to reduce potential measurement error due to selection bias, but which limited the evaluation generalizability. Reliability was addressed by aligning the research purpose and study design, and conducting key informant interviews using pilot-tested moderator's guides and a trained interviewer. Lastly, the study focus was the Alaska Native population, which potentially limits the generalizability of the study findings to other racial/ethnic groups or to the broader U.S. population.

Influences on screening behaviors are numerous and complex. Individual, interpersonal, organizational, community, and policy level factors all impact screening uptake. This study provided novel information on CRC screening outreach activities occurring across the ATHS, and challenges experienced by those working to increase CRC screening in the Alaska tribal health setting. It also explored the Alaska Native CRC Family Outreach Program, which is unique in providing active outreach to tribal FDRs of CRC patients. By closely examining the successes and barriers to increasing CRC screening experienced throughout the ATHS and within the Alaska Native CRC Family Outreach Program, the study was able to identify significant gaps and areas for research and policy improvement. The study findings highlight key issues that are faced by many tribal, urban Indian, and Indian Health Services facilities, as well as other healthcare delivery systems nationwide seeking to promote CRC screening among increased-risk patients. These data also have broader relevance for other programs working to increase health-seeking behaviors among populations experiencing significant health disparities. Further

research is needed to inform CRC screening interventions among Alaska Native people to help reduce morbidity and mortality due to this preventable disease.

Literature Cited

1. Rees G, Martin PR, Macrae FA. Screening participation in individuals with a family history of colorectal cancer: a review. Eur J Cancer Care (Engl). 2008 May;17(3):221-32.

2. Madlensky L, Esplen MJ, Gallinger S, McLaughlin JR, Goel V. Relatives of colorectal cancer patients: factors associated with screening behavior. Am J Prev Med. 2003 Oct;25(3):187-94.

3. Elkin EB, Shapiro E, Snow JG, Zauber AG, Krauskopf MS. The economic impact of a patient navigator program to increase screening colonoscopy. Cancer. 2012 Dec 1;118(23):5982-8.

4. Freeman HP, Rodriguez RL. History and principles of patient navigation. Cancer. 2011 Aug;117(15 Suppl):3539-42.

5. Lasser KE, Murillo J, Medlin E, Lisboa S, Valley-Shah L, Fletcher RH, et al. A multilevel intervention to promote colorectal cancer screening among community health center patients: results of a pilot study. BMC Fam Pract. 2009;10:37.

6. Redwood D, Provost E, Perdue D, Haverkamp D, Espey D. The last frontier: innovative efforts to reduce colorectal cancer disparities among the remote Alaska Native population. Gastrointest Endosc. 2012 Mar;75(3):474-80.

7. Nash D, Azeez S, Vlahov D, Schori M. Evaluation of an intervention to increase screening colonoscopy in an urban public hospital setting. J Urban Health. 2006 Mar;83(2):231-43.

8. Daley CM, James AS, Filippi M, Weir M, Braiuca S, Kaur B, et al. American Indian Community Leader and Provider Views of Needs and Barriers to Colorectal Cancer Screening. Journal of health disparities research and practice. 2012;5(2).

9. Beydoun HA, Beydoun MA. Predictors of colorectal cancer screening behaviors among average-risk older adults in the United States. Cancer Causes Control. 2008 May;19(4):339-59.

10. Wilkins T, Gillies RA, Harbuck S, Garren J, Looney SW, Schade RR. Racial disparities and barriers to colorectal cancer screening in rural areas. J Am Board Fam Med. 2012 May-Jun;25(3):308-17.

11. Haverkamp D, Perdue DG, Espey D, Cobb N. A survey of Indian Health Service and tribal health providers' colorectal cancer screening knowledge, perceptions, and practices. J Health Care Poor Underserved. 2011 Feb;22(1):243-57.

12. Klabunde CN, Frame PS, Meadow A, Jones E, Nadel M, Vernon SW. A national survey of primary care physicians' colorectal cancer screening recommendations and practices. Prev Med. 2003 Mar;36(3):352-62.

13. Sarfaty M. How to Increase Colorectal Cancer Screening Rates in Practice: A Primary Care Clinician’s Evidence-Based Toolbox and Guide: The American Cancer Society 2008.

14. Nease DE, Jr., Ruffin MTt, Klinkman MS, Jimbo M, Braun TM, Underwood JM. Impact of a generalizable reminder system on colorectal cancer screening in diverse primary care practices: a report from the prompting and reminding at encounters for prevention project. Med Care. 2008 Sep;46(9 Suppl 1):S68-73.

15. Baron RC, Melillo S, Rimer BK, Coates RJ, Kerner J, Habarta N, et al. Intervention to increase recommendation and delivery of screening for breast, cervical, and colorectal cancers by healthcare providers a systematic review of provider reminders. Am J Prev Med. 2010 Jan;38(1):110-7.

16. Klabunde CN, Lanier D, Breslau ES, Zapka JG, Fletcher RH, Ransohoff DF, et al. Improving colorectal cancer screening in primary care practice: innovative strategies and future directions. J Gen Intern Med. 2007 Aug;22(8):1195-205.

17. Lacy NL, Paulman A, Reuter MD, Lovejoy B. Why we don't come: patient perceptions on no-shows. Ann Fam Med. 2004 Nov-Dec;2(6):541-5.

18. Harris MJ. Evaluating public and community health programs. San Francisco, CA: Jossey-Bass; 2010.

Appendices

Appendix A

Use of Family History for Colorectal Cancer Screening Outreach Survey, 2012

Introduction: Hello, my name is _____. I work in cancer prevention at the Alaska Native Tribal Health Consortium. In collaboration with the Indian Health Service, we are trying to learn how tribal health facilities manage outreach to encourage patients to get colorectal cancer screening.

1.) Would you be the appropriate person to discuss colorectal cancer screening outreach at your facility?

Yes (go to Background and Q. 2) **No** **Don't know**

If no, who would you recommend speaking with about this?

a. Name:
   _____
b. Contact Info:
   _____
   _____

Thank you for your time.

Background: We'd like to collect information from tribal health facilities in Alaska about how family history is being used for colorectal cancer screening outreach. Your input will help to make recommendations for improving CRC screening and should take about 5 minutes of your time. Is now a good time for you to answer a few questions on this?

If not, when would be a better day and time to discuss this with you? _____

I. Screening Outreach

2.) Does your facility provide **outreach to encourage patients** to get CRC screening?

Yes (go to Q. 3) **No (go to Q. 11)** **Don't know**

3.) What kinds of outreach do you do?

Now I am going to ask you about specific CRC screening outreach methods at your facility.

4.) What materials do you use for CRC screening outreach?

a. Patient Wellness Handouts (such as brochures) **Yes No (skip to b) DK**
   i. Do most of your providers use them? **Yes No DK**
   ii. Are these useful for encouraging screening? **Yes No DK**
   iii. Are these sufficient for encouraging screening? **Yes No DK**
b. Provider reminders? **Yes No (skip to c) DK**
   i. Do most of your providers use them? **Yes No DK**
   ii. Are these useful for encouraging screening? **Yes No DK**
   iii. Are these sufficient for encouraging screening? **Ye No DK**
c. Mailed patient reminders? **Yes No (skip to d) DK**
   i. Do most of your providers use them? **Yes No DK**
   ii. Are these useful for encouraging screening? **Yes No DK**
   iii. Are these sufficient for encouraging screening? **Yes No DK**
d. Phone patient reminders? **Yes No (skip to e) DK**
   i. Do most of your providers use them? **Yes No DK**
   ii. Are these useful for encouraging screening? **Yes No DK**
   iii. Are these sufficient for encouraging screening? **Yes No DK**
e. Other types of CRC screening outreach (explain)? **Yes No Don't know**

   _____

   _____

   _____

   i. Do most of your providers use them? **Yes No Don't know**

5.) Does your facility provide CRC screening outreach specifically to **family members** of patients with colorectal cancer?

Yes (go to Q. 6) No (go to Q. 10) Don't know

6.) What type of outreach do you provide specifically for **family members** of CRC patients?

a. Patient Wellness Handouts? **Yes No (skip to b) Don't know**
   i. Do most of your providers use them? **Yes No Don't know**
b. Provider reminders? **Yes No (skip to c) Don't know**
   i. Do most of your providers use them? **Yes No Don't know**
c. Mailed patient reminders? **Yes No (skip to d) Don't know**
   i. Do most of your providers use them? **Yes No Don't know**
d. Phone patient reminders? **Yes No (skip to e) Don't know**
   i. Do most of your providers use them? **Yes No Don't know**
e. Other tools for CRC screening outreach purposes (explain)? **Yes No DK**

7.) Does your facility provide anything beyond that for **first degree relatives (parents, siblings, children)** of patients with colorectal cancer?

Yes (go to Q. 8) **No (go to Q. 10)** **Don't know**

8.) What type of outreach do you do specifically for **first degree relatives** of patients with CRC beyond what you may do for family members in general?

_____

_____

9.) Do you collect information on first degree family members of CRC patients?

Yes (go to Q. 10) **No (go to Q. 11)** **Don't know**

10.) How do you identify first degree family members of CRC patients?

a. Ask CRC patients for family history lists? **Yes No (skip to d) DK**
   i. How are CRC patients identified?
      _____
      _____
   ii. Who collects the family history information?
      _____
      _____
   iii. Where is that information put?
      _____
      _____

b. Take family history when patient comes in to provider? **Yes No (skip to e) DK**
   i. Who collects the family history information?
      _____
      _____
   ii. Where is that information put?
      _____
      _____

c. In the electronic medical record? **Yes No (skip to b) DK No EMR**
   i. How does information get into the electronic medical record?
      _____
      _____
   ii. Where is that information put?
      _____
      _____

d. In the patient chart? **Yes No (skip to c) Don't know**

i. How does information get into the patient's chart?

_____

_____

ii. Where is that information put?

_____

iii. Other methods (explain)? **Yes** **No** **Don't know**

_____

_____

e. How often is the information updated (explain)?

_____

_____

(Go to Q. 12)

*****If no to Q. 2**:

11.) If your facility does not offer CRC screening outreach to patients what are some of the reasons?

_____

_____

12.) What do you think would help your facility expand CRC screening outreach to patients?

_____

_____

13.) If the Indian Health Service was to develop a toolkit with CRC screening materials and outreach tips how might it be helpful for your facility?

_____

_____

a. What types of items in a CRC screening outreach toolkit do you think would be most helpful for your facility?

_____

_____

b. Who in your facility do you think would use it?

_____

_____

II. Demographics

1.) Facility Name:_____

2.) Facility location (city, state):
_____

3.) Facility Point Person:
_____

   a. Facility Contact title:
   _____

   b. Facility Contact email:
   _____

   c. Facility Contact phone number:
   _____

4.) Facility Contact address:
_____
_____

5.) Do you consider your facility a (circle one)?
   a. Indian Health Service
   b. Tribal
   c. Urban
   d. Other (explain):
   _____

6.) Is there anyone else at your facility that you would recommend talking to about this?

Yes No Don't know

If so, please list the name and contact information below

_____

Thank you for your time and assistance. After we finish the survey we will compile an aggregated report which we will provide back to you at the end of the project.
If you have any additional questions or comments please contact Diana Redwood at dredwood@anthc.org or 907-729-3959.

APPENDIX B

CRC Family History Outreach Program Evaluation Key Informant Interview Moderator Guide, 2012

Name: _____ Day: _____

Position: _____ Time: _____

The focus of this evaluation will be to better understand how the CRC Family History Outreach Program is operating in the Alaska Tribal Health System as well as learn what effect it has had on CRC screening among Alaska Native people. Input from this evaluation will be shared with staff and funders in order to make improvements in program implementation.

My purpose in talking with you today is to learn more about your thoughts, feelings and experiences with the CRC Family History Outreach Program.

Anything you tell me will not be personally attributed to you in any reports that result from this evaluation. All of the reports will be written in a manner that no individual comment can be attributed to a particular person.

Your participation in this interview is completely voluntary. Are you willing to be interviewed?

Do you have any questions before we begin?

(Note: Not all questions will be asked of all interviewees)

Interview Questions

1. What is your role with the program?
2. How did you get involved with the program? When?
3. How did the program come to exist?
4. How have you seen it change?
5. What do you think are the strengths of the program? Weaknesses?
6. Was there a specific amount of funding available to run the program? How much? When did funding start?

7. Were staff assigned to the program outreach efforts actually able to spend time doing outreach, or were they pulled into other work activities? How many FTEs were devoted to the program?
8. Was there continuous access to the electronic medical record available to program staff in order to identify first-degree relatives who had been screened?
9. When did CRC patients start being contacted to obtain a list ("family history lists") with contact information of their first degree relatives (siblings, parents, children)?
10. Were family history lists that were obtained all entered into the database?
11. Were first-degree relatives called/sent letters to encourage them to get screened?
12. How many outreach efforts (phone calls/letters) were made?
13. Were outreach efforts recorded/tracked in the database?
14. Was the electronic medical record data merge with the family history database completed?
15. How effective is the Program at getting AN people screened for CRC?
16. Which program components have been the most successful for implementing the Program?
17. Why did relatives who got screened make that health behavior change?
18. What are your impressions of how Alaska Native first-degree relatives have been affected by the Program? (Probe: increased screening, knowledge of CRC—ask for examples)
19. What were the barriers to program success previously, and what are the barriers now?
20. What were the facilitators to program success previously, and what are the facilitators now?
21. How has ANTHC ensured the sustainability of the Program?
22. Do you have any additional comments about the Program that we have not already discussed?

Thank you for your time!

Alaska Area Institutional Review Board
4315 Diplomacy Drive - RMCC
Anchorage, AK 99508
Phone: (907) 729-3924

DATE:	August 23, 2011
TO:	Diana Redwood, MS, MPH Principal Investigator, Alaska Native Epidemiology Center, 4000 Ambassador Drive, Anchorage, AK 99508
FROM:	Alaska Area Institutional Review Board (IHS IRB #2)
STUDY TITLE:	[219334-1] Use of Family History for Improved Colorectal Cancer Screening Outreach Among Alaska Native and American Indian People
IRB REFERENCE #:	2011-02-003
SUBMISSION TYPE:	New Project
ACTION:	DETERMINATION OF EXEMPT STATUS
DECISION DATE:	July 19, 2011
REVIEW CATEGORY:	Exemption per 45 CFR 46.101(b)

Dear Ms. Redwood:

Thank you for your submission of New Project materials for this research study. Alaska Area Institutional Review Board (IHS IRB #2) has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations. All modifications to the project must be reviewed in advance by the Alaska Area IRB for this decision to remain valid.

Tribal review and approval is required for exempt research. The IRB requires a privacy review with the ANTHC Privacy Officer and the Southcentral Foundation Privacy Officer. We will put a copy of this correspondence on file in our office.

If you have further questions for the Alaska Area IRB you may contact me at tjpowell@anthc.org or call (907) 729-3924.

Sincerely,

Terry J. M. Powell
Alaska Area Institutional Review Board
IRB Administrator
4315 Diplomacy Drive RMCC
Anchorage, Alaska 99508

(907) 474-7800
(907) 474-5444 fax
fyirb@uaf.edu
www.uaf.edu/irb

Institutional Review Board

909 N Koyukuk Dr. Suite 212, P.O. Box 757270, Fairbanks, Alaska 99775-7270

September 30, 2011

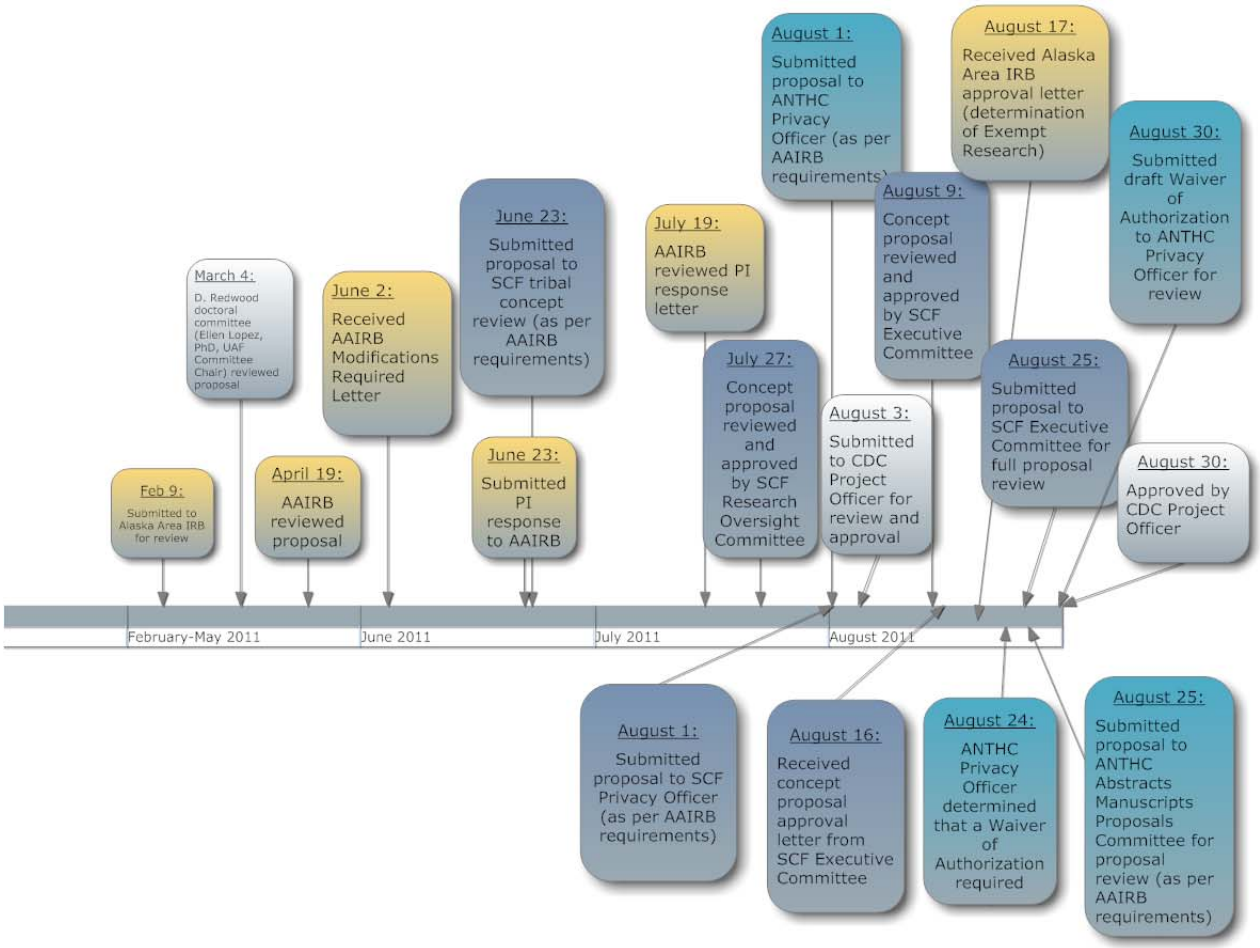
To:	Ellen Lopez, PhD Principal Investigator
From:	University of Alaska Fairbanks IRB
Re:	[234570-1] Use of Family History for Improved Colorectal Cancer Screening Outreach Among Alaska Native and American Indian People

Thank you for submitting the New Project referenced below. The submission was handled by Administrative Review. The Office of Research Integrity has determined that the proposed research qualifies for exemption from the requirements of 45 CFR 46. This exemption does not waive the researchers' responsibility to adhere to basic ethical principles for the responsible conduct of research and discipline specific professional standards.

Title:	Use of Family History for Improved Colorectal Cancer Screening Outreach Among Alaska Native and American Indian People
Received:	September 20, 2011
Exemption Category:	*4*
Effective Date:	September 30, 2011

This action is included on the October 13, 2011 IRB Agenda.

Prior to making substantive changes to the scope of research, research tools, or personnel involved on the project, please contact the Office of Research Integrity to determine whether or not additional review is required. Additional review is not required for small editorial changes to improve the clarity or readability of the research tools or other documents.



Alaska Area IRB and Tribal Review Timeline: February - August, 2011
Family History Outreach Program Evaluation

Timeline Key: AAIRB events (yellow), Southcentral Foundation (SCF) events (dark blue), Alaska Native Tribal Health Consortium (ANTHC) events (light blue), other events (grey)

Alaska Area IRB and Tribal Review Timeline:
September - November, 2011
Family History Outreach Program Evaluation

Timeline Key: AAIRB events (yellow), SCF events (dark blue), ANTHC events (light blue), other events (grey)